

The benefit of neighbourhood social capital for health of people with chronic illness

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The benefit of neighbourhood social capital for health of people with chronic illness

Het effect van buurt sociaal kapitaal op de gezondheid van mensen met een chronische ziekte

(met een samenvatting in het Nederlands)

PROEFSCHRIFT

ter verkrijging van de graad van doctor aan de Universiteit Utrecht op gezag van de rector magnificus, prof. dr. G.J. van der Zwaan, ingevolge het besluit van het college voor promoties in het openbaar te verdedigen op woensdag 10 januari 2018 des middags te 2.30 uur

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1

General introduction

Individual health and well-being are influenced by the social contexts people belong to, and are not only dependent on individual characteristics. One of the ways through which social influences on health and well-being can operate are the neighbourhoods, that people live in. The neighbourhood context may exert an effect on individual life chances, independent of personal characteristics, knowledge and capabilities. Both physical and social characteristics of the neighbourhood have been examined in relationship to individual health and well-being (Diez Roux and Mair, 2010). The social neighbourhood environment includes, among others, the social connections and friendships between neighbours, the presence of social norms, stigmatization, peer pressure, reciprocity, safety and violence. It has been hypothesized that connections between neighbours generate resources and support that can benefit health and well-being. These resources can be referred to as social capital. Neighbourhood social capital does not inhere in specific relationships between neighbours, but is a characteristic of the neighbourhood community. This means that neighbourhood social capital can also provide resources for people who are not personally connected to specific others in their neighbourhood. Many studies among the general population have found that people living in neighbourhoods with more neighbourhood social capital experience better health, independent of socio-demographic characteristics of the residents (Gilbert et al., 2013; Islam et al., 2006; Kawachi et al., 2007; Lochner et al., 2003; Mohnen et al., 2011; Murayama et al., 2012). The aim of this thesis is to apply social capital theory to gain more insight into the benefit of neighbourhood social capital for health of people with chronic illness. People with chronic illness are faced with a number of tasks related to dealing with the symptoms, treatment, physical, psychological and social consequences of a chronic illness as well as necessary lifestyle adjustments (CBO, 2001). People with chronic illness may use resources provided through neighbourhood social capital to deal with the tasks and the limitations they are faced with due to their illness. The main question of this thesis is:

Is neighbourhood social capital related to health of people with chronic illness? And if so, how can we explain the relationship between neighbourhood social capital and health of people with chronic illness?

This introductory chapter will shed light on the term ‘neighbourhood social capital’, what resources it may provide for individual health, and how it can

benefit health of people with chronic illness. Consequently this chapter will introduce the research questions and hypotheses of this thesis.

Neighbourhood social capital

Social capital

The fundamental ideas behind social capital have largely been introduced by the work of Pierre Bourdieu, James Coleman and Robert Putnam. This thesis views social capital in line with Coleman's definition. Coleman (1988) defines social capital as the source of collective resources that are generated through, and embedded in, the relations between members of a community. He emphasizes the productive nature of social capital and states that social capital can be used to reach goals. Coleman discusses the benefit of social capital in relation to sales at the Jewish diamond market. He states that close ties between traders, through family, community, and religious affiliation, provide the trust that is necessary to facilitate the transactions. He also describes how social capital can contribute to a feeling of safety by guaranteeing that unattended children will be looked after by other adults. Next to these examples of the benefit of social capital, other studies among the general population have found that social capital can provide access to information about jobs (Granovetter, 1973), can enhance well-being (Van Dijk et al., 2013), and can buffer some of the effects of low socioeconomic status on health (Uphoff et al., 2013). This thesis will focus on the benefit of neighbourhood social capital for health of people with chronic illness. Neighbourhood social capital differs from individual social capital. Neighbourhood social capital refers to the web of relationships between people in a neighbourhood, at the individual level social capital refers to resources generated in the relationship between specific individuals. In this thesis, neighbourhood social capital is considered as the source of collective resources that are embedded in relationships between people in a neighbourhood.

Neighbourhood social capital and health

Many studies among the general population have found that people living in neighbourhoods with more neighbourhood social capital experience better health, independent of socio-demographic characteristics of the residents (see for instance these studies and reviews about neighbourhood social capital and

health: Gilbert et al., 2013; Islam et al., 2006; Kawachi et al., 2007; Lochner et al., 2003; Mohnen et al., 2011; Murayama et al., 2012).

To date it is unclear whether neighbourhood social capital influences individual health or whether individual health influences the development of neighbourhood social capital. In neighbourhoods where people are in better health, there might be more opportunities for interaction between neighbours and the development of neighbourhood social capital. It is also possible that there is merely a correlation between neighbourhood social capital and health instead of a causal relationship, because people with better health are selected into neighbourhoods with more social capital. The majority of studies investigating the relationship between neighbourhood social capital and health are cross-sectional. Cross-sectional studies are unable to shed light on the direction of the relationship between neighbourhood social capital and health (Murayama et al., 2012).

There is also little clarity about which collective resources are generated through social contacts between people in a neighbourhood. Neighbourhood social capital might influence individual health through social, behavioural and psychological mechanisms. A number of mechanisms have been proposed in the literature:

1. Neighbourhood social capital may exert an effect on health through the promotion of access to local services and amenities (Kawachi et al., 1999; Kawachi and Berkman, 2000). Neighbourhoods with more social capital might be more successful at undertaking collective action to ensure access to health promoting services and amenities. In support of this hypothesis it has been found that people living in communities with more social capital experience fewer problems with access to healthcare (Hendryx et al., 2002; Derose and Varda, 2009).
2. People living in neighbourhoods with more social capital might benefit from affective and instrumental support provided by neighbours. Studies have shown that neighbours can provide support for tasks that require proximity (such as monitoring that someone is okay), tasks that are practical (for instance shopping, transportation or assistance with household maintenance) and non-intimate (not concerning personal care or nursing tasks for instance

(Barker, 2002; Bridge, 2002; LaPierre and Keating, 2013; Litwak and Szelenyi, 1969; Nocon and Pearson, 2000).

3. Neighbourhood social capital may promote the diffusion of health-related information and therefore increase the likelihood that healthy behaviour is adopted (Kawachi et al., 1999; Kawachi et al., 2000).
4. Neighbourhood social capital may exert an influence on health by social control over deviant or unhealthy behaviour (Kawachi et al., 1999; Kawachi et al., 2000). Social capital may prevent crime and delinquent behaviour, but may also prevent other forms of deviant behaviour, such as public drinking, smoking or drug abuse.

Neighbourhood social capital and health of people with chronic illness

People with chronic illness may benefit from neighbourhood social capital to deal with the tasks and limitations they face due to their illness. During the last decades, there has been increasing emphasis on self-management of chronic illness and individual responsibility for acquiring social network support. In the Netherlands emphasis on self-management and individual responsibility grew with the introduction of the Social Support Act (Wmo) in 2007. With the Social Support Act a greater part of the responsibility for the provision of support for vulnerable groups was delegated to municipalities (Kroneman et al., 2016). With the Social Support Act municipalities became responsible for providing support for people with physical, psychological, intellectual or psychosocial disabilities or problems. This includes people with chronic illness, as they may experience physical disabilities or problems as a consequence of their illness. Also due to limited financial resources of local governments, people with chronic illness are stimulated to utilize social network support and neighbourhood resources before appealing to municipal services. The goal of support provided by the municipality is to facilitate people to self-manage their health problems, to continue living in their own home and participate in society. Support provided by the municipality includes, among others, domiciliary help, adaptation of the house, meal supply, a lending point for wheelchairs and sports facilities for disabled people.

With the emphasis on chronic illness self-management and participation, the question arises what determines whether people with chronic illness are able to manage their illness and promote health. To date, many studies have focused on individual determinants of health and self-management such as self-management skills, motivation and self-efficacy. However, not all people with chronic illness are equally capable of self-management. There is a difference between what is expected of citizens and what they can truly handle (The Netherlands Scientific Council for Government Policy, 2017). People with chronic illness may not always have the ability to think clearly, undertake action for their health when it is needed or hold on to good intentions about lifestyle changes. They might not always be able to set goals, make plans, and deal with setbacks in their health. To manage their health, people with chronic illness may need support. If people with chronic illness are in need of support for self-management, they can draw on support from healthcare providers. Healthcare providers can help people with chronic illness by providing information about medication, treatment options and symptom management, by helping them to build confidence and by encouraging them to make choices that lead to improved health-outcomes (Bodenheimer et al., 2006; Glasgow et al., 2003; Wagner et al., 2001). However, self-management support is not the exclusive domain of healthcare professionals. The largest part of self-management takes place outside the healthcare setting. Therefore, people with chronic illness may also need to draw on other resources and support to promote health and self-management in daily life. This thesis aims to gain insight into the way neighbourhood resources can contribute to health of people with chronic illness.

Mechanisms behind the relationship between neighbourhood social capital and health of people with chronic illness

This thesis will test a number of possible mechanisms behind the relationship between neighbourhood social capital and health of people with chronic illness, namely:

1. Increased access to health promoting services and amenities;
2. the provision of affective and instrumental support by neighbours;
3. improved chronic illness self-management;
4. increased access to health information.

Why are these mechanisms specifically relevant for people with chronic illness? First of all, services and amenities in municipalities are aimed at promoting self-management, wellbeing and participation. People with chronic illness may use these services and amenities to benefit health. Therefore, it is important to study whether neighbourhood social capital increases the willingness and capability of people to lobby for increased access to these services and amenities.

Secondly, people with chronic illness may benefit from affective and instrumental support from neighbours to promote health and self-management. Support by neighbours may help people with chronic illness to deal with the tasks and limitations they face due to their health condition.

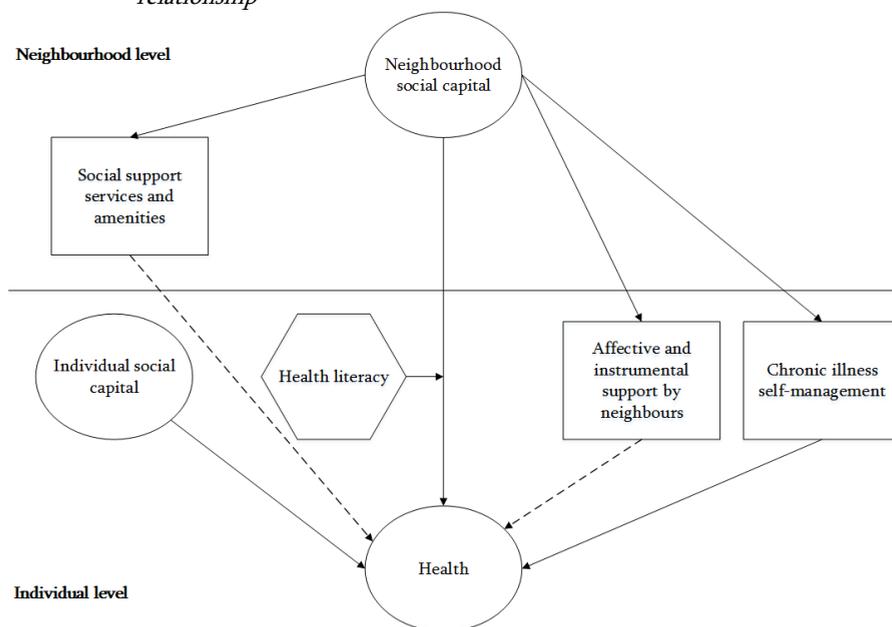
Thirdly, the resources mentioned above, access to health promoting services and amenities and access to support by neighbours, may benefit health because they contribute to improved chronic illness self-management.

Fourthly, people with chronic illness need health literacy skills to gain access to, understand and apply health information to make decisions about health. For instance about the symptoms they experience, the healthcare they need, medication or lifestyle changes. Increased access to health information in neighbourhoods can help people with chronic illness to make these decisions and may compensate for a lack of health literacy skills needed to independently access and apply health information.

Research questions and hypotheses

The next section will elaborate on the research questions and the hypotheses that will be tested in this thesis. Figure 1.1 illustrates the relationships that will be examined in this thesis. This figure will be further explained in the remainder of this chapter.

Figure 1.1 Conceptual model of the relationship between neighbourhood social capital and health of people with chronic illness and mechanisms behind this relationship



* The striped line signifies a relationship that is assumed but is not actually tested in this thesis.

Establishing the relationship between neighbourhood social capital and health of people with chronic illness

The first study of this thesis will establish whether there is a causal relationship between neighbourhood social capital and health of people with chronic illness, beyond individual connections to neighbours. As previously mentioned, neighbourhood social capital refers to the web of relationships between people in a community. At the individual level social capital refers to resources generated in the relationship between specific individuals. The results of this study will shed light on the question whether people with chronic illness who are not personally connected to people in their neighbourhood, can still benefit from neighbourhood social capital. Halpern (2005) argues that individual social capital should be included in the study of neighbourhood social capital. Neglecting to take into account the effect of individual social capital produces the risk of incorrectly attributing resources generated in the relationship between specific individuals, to the neighbourhood environment. This study will therefore take into account individual level social capital by using a multilevel framework. This

study will focus on the effect of neighbourhood social capital on changes in health. By studying the relationship between neighbourhood social capital and health longitudinally, it is possible to establish whether there is a causal relationship between neighbourhood social capital and health of people with chronic illness. The research question this study aims to answer is:

Does social capital, on the individual and on the neighbourhood level, influence changes in health of people with chronic illness?

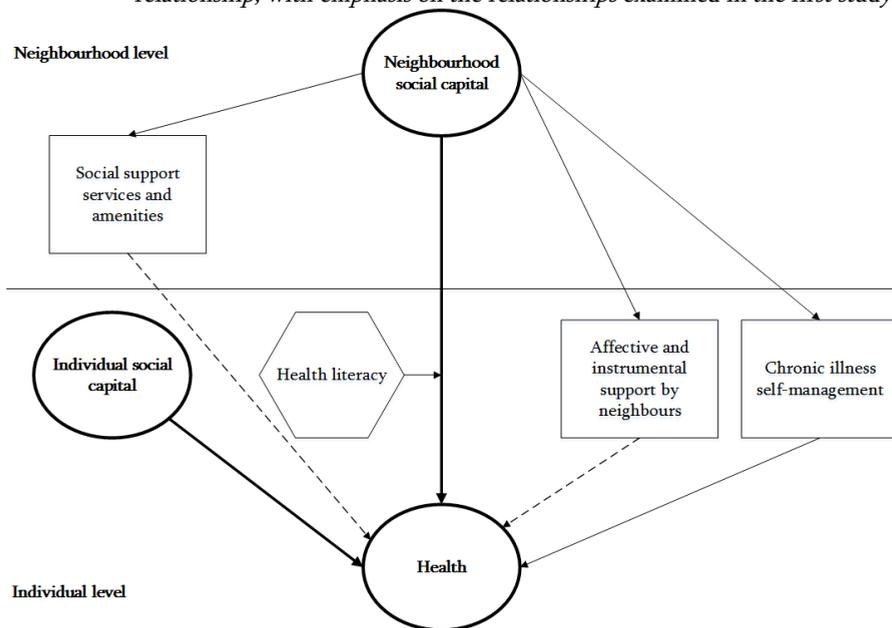
This study will test the following hypothesis:

Hypothesis 1

A higher level of neighbourhood social capital exerts a positive influence on changes in the self-rated health of people with a chronic illness, beyond individual connections to neighbours.

The bold shapes in figure 1.2 identify the relationships that are examined in this study.

Figure 1.2 Conceptual model of the relationship between neighbourhood social capital and health of people with chronic illness and mechanisms behind this relationship, with emphasis on the relationships examined in the first study



How do people with chronic illness view the contributions of neighbours and other social network members to health and self-management?

This thesis will continue with a qualitative study to gain insight into the views of people with chronic illness on the contributions of neighbours, and other social network members, to health and self-management.

The contribution of the social network to health and self-management has become an increasingly relevant topic in contemporary policy debates. To contain the utilization of professional healthcare and support services, the social network is expected to fulfil support needs of people of chronic illness. There is increasing evidence that the social network makes important contributions to health and self-management of people with chronic illness (Kendal and Rogers, 2007; Vassilev et al., 2013; Vassilev et al., 2014). Studies have shown that friends and family provide support in a number of different ways, e.g. by helping in the household, providing transportation, assisting people in contact with healthcare professionals, by support for psychosocial adjustment to the illness, support for medication management, doing groceries or help with exercise (De Boer and De Klerk, 2013; De Klerk et al., 2014; Dwarswaard et al., 2016; Gallant, 2003; Rosland and Piette, 2010; Sayers et al., 2008). Although, social network support is important, it might not always be available to people with chronic illness. Female labour participation, smaller family sizes, and greater geographic dispersal of families might reduce the availability of informal caregivers (De Klerk et al., 2009; LaPlante et al., 2001; Linders, 2010; Lowenstein and Daatland, 2006). People with chronic illness might also be reluctant to ask support from their social network. For instance, because they experience a lack of autonomy when they accept support from their social network (Janlöv et al., 2005; Kwak et al., 2014), because they feel uncomfortable with a lack of reciprocity in a relationship (McCann and Evans, 2002; Newsom, 1999; Wolff and Agree, 2004), or because they do not want to burden others (Linders, 2010; Cahill et al., 2010). To date, most of the studies investigating social network support have focused on the support of close relatives such as partners and children (LaPierre and Keating, 2013; Nocon and Pearson, 2000; Rogers et al., 2014). Furthermore, studies investigating barriers to ask and receive support have also predominantly focused on care and support by partners and children (see for instance: Martire et al., 2002; Newsom and Schulz, 1998; Wolff and Agree, 2004). However, assistance from other social network members, such as friends and neighbours, can serve a critical role in helping people with health problems to stay in their

own home. For instance by fulfilling practical tasks such as monitoring that someone is okay, help with grocery shopping, providing transportation or assistance with chores in and around the house (Barker, 2002; Bridge, 2002; Egging et al., 2011; Lapierre et al., 2013; Litwak and Szelenyi, 1969; Nocon et al., 2002). Care and support by other social network members, such as friends and neighbours, can substitute care and support from partners and children when this is not adequately available (Barker, 2002) or can supplement care and support received from partners and children. The second study of this thesis will present a picture of self-management support by different social ties, amongst whom are neighbours. The research questions this study aims to answer are:

- 1. How do social network members outside the nuclear family support chronic illness self-management?*
- 2. What barriers do people with chronic illness experience to ask and receive support from social network members?*

After this qualitative study, this thesis will go on to focus specifically on the mechanisms behind the relationship between neighbourhood social capital and health of people with chronic illness.

Increased access to health promoting services and amenities as a mechanism behind the relationship between neighbourhood social capital and health of people with chronic illness

As mentioned previously in this chapter, one of the mechanisms behind the relationship between social capital and health may be the differential provision of public services and amenities (Kawachi et al., 1999; Kawachi et al., 2000). Social capital might lead to improved access to services and amenities because in communities where people are more connected there might be a higher capacity to work cooperatively to reach shared goals (Frieling et al., 2012; Kawachi et al., 1999; Kilpatrick and Abbott-Chapman, 2005; Putnam, 2000; Sampson et al., 1997). Examples include the ability to protest the closure of a local hospital, or the ability to lobby to restrict smoking in public places. Altschuler and Adler (2004) describe how neighbourhoods mobilized to respond to threats to the liveability of the neighbourhood and neighbourhood amenities. Neighbours drew upon social capital to become active and they battled threats to neighbourhood safety, such as speeding in their neighbourhood, drug dealing, and excessive numbers of liquor stores. Social capital can lead to collective action for the public good if it coincides with so called 'collective efficacy'. Collective

efficacy can be described as the extent to which people are willing to work for a common goal and want to intervene on behalf of the common good (Sampson et al., 1997). One of the common goals residents can work towards is increasing access to health-promoting services and amenities. In the Netherlands, municipalities are responsible for developing a coherent social support policy (Kroneman et al., 2016; Schäfer et al., 2010). Municipalities vary in the development and implementation of local support policy (Van Houten et al., 2008). Therefore, the situation in the Netherlands provides a good case to study the relationship between social capital, collective efficacy and the provision of social support services and amenities for people who experience limitations to their participation in society (such as people with chronic illness, disabled people, or elderly people). The third study of this thesis will investigate the relationship between neighbourhood social capital, collective efficacy and the provision of municipal services and amenities. The research question this study aims to answer is:

Does differential provision of services and amenities explain the relationship between neighbourhood social capital and health?

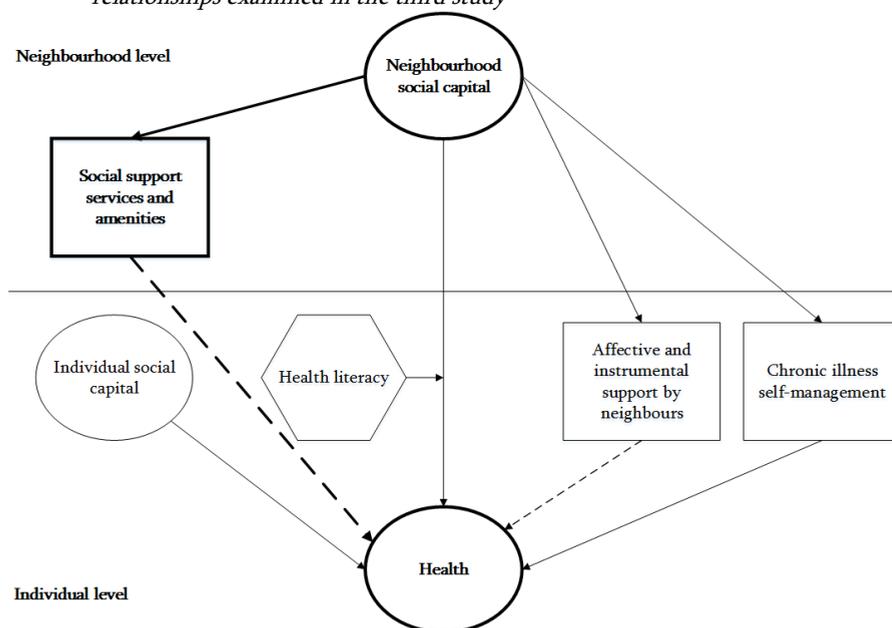
This study will test the following hypothesis:

Hypothesis 2

Social capital in combination with collective efficacy is positively related to the provision of social support services and amenities by municipalities.

The bold shapes in figure 1.3 identify the relationships that are examined in this study.

Figure 1.3 Conceptual model of the relationship between neighbourhood social capital and health and mechanisms behind this relationship, with emphasis on the relationships examined in the third study



* The striped line signifies a relationship that is assumed but is not actually tested in this thesis.

The provision of affective and instrumental support by neighbours as a mechanism behind the relationship between neighbourhood social capital and health of people with chronic illness

Next to increased access to health-promoting services and amenities, people with chronic illness in neighbourhoods with more social capital may also benefit from affective and instrumental support by neighbours (Kawachi et al., 1999; Kawachi et al., 2000). There has been an increasing focus on the responsibility of patients and their social network for health and self-management of health problems (Lipszyc et al., 2012; Maarse and Jeurissen, 2016). As mentioned previously, people with chronic illness may not always be able to rely on support for health and self-management from close social ties such as friends and family. When there are barriers to support from friends and family, or when people with chronic illness otherwise lack the resources they need for health, the neighbourhood can possibly provide compensatory resources. A previous study found that people with less frequent contact with friends and family were more likely to report good health when they lived in neighbourhoods with more social

capital (Mohnen et al., 2015). In a neighbourhood with more social capital there might be more of a general tendency to help each other (for instance with work in the garden, carrying groceries, or by having a conversation on the street), even when people don't know each other very well. Others, however, stress the importance of being personally connected to people or networks that generate specific resources. Carpiano states that access to social support is restricted to people who are embedded in specific relationships with those that can provide social support (Carpiano, 2006; Carpiano, 2008). Simply living in a neighbourhood with more social capital, without having relationships with specific neighbours or being integrated into neighbourhood networks, might not be enough for people with chronic illness to gain access to support by neighbours. The fourth study of this thesis will examine the relationship between support by neighbours, neighbourhood social capital and individual social capital. The research question this study aims to answer is:

Do people with chronic illness who live in neighbourhoods with more social capital more often receive affective and instrumental support from neighbours?

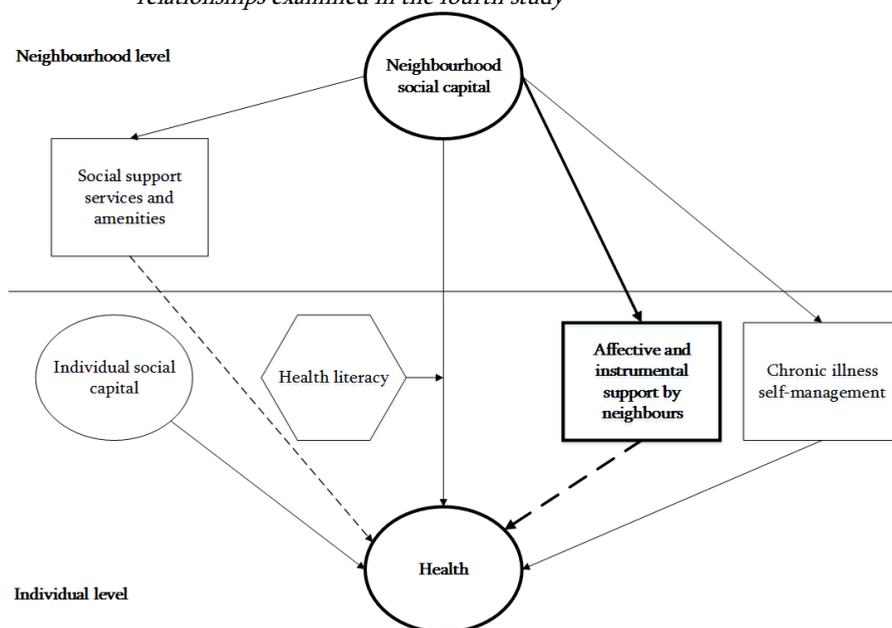
This study will test the following hypothesis:

Hypothesis:

People with chronic illness more often receive affective and instrumental support from neighbours if they live in neighbourhoods with more social capital, beyond individual connections to neighbours.

The bold shapes in figure 1.4 identify the relationships that are examined in this study.

Figure 1.4 Conceptual model of the relationship between neighbourhood social capital and health and mechanisms behind this relationship, with emphasis on the relationships examined in the fourth study



* The striped line signifies a relationship that is assumed but is not actually tested in this thesis.

Improved chronic illness self-management as a mechanism behind the relationship between neighbourhood social capital and health of people with chronic illness

As previously mentioned, neighbourhood social capital might contribute to health of people with chronic illness by providing resources for chronic illness self-management.

Managing a chronic illness goes beyond medical tasks and also includes practical tasks that are performed in and around the home and in the neighbourhood, such as domestic work, food shopping, symptom monitoring, taking medication, and exercise. Furthermore, self-management also includes negotiating the effect of a chronic illness on relationships with a partner, children, family and friends. Chronic illness self-management can be defined as dealing with a chronic condition (its symptoms, treatment, physical, psychological and social consequences as well as necessary lifestyle adjustments) in such a way that the condition can be integrated in one's life. Self-management also means that people

have the power to decide to what extent they want to be involved in decisions about healthcare to maintain or reach an optimal quality of life (CBO, 2001).

Among the resources that may benefit chronic illness self-management are: increased provision of health promoting services and amenities, the provision of affective and instrumental support by neighbours, and increased access to health information. The studies in this thesis will each focus on a specific resource provided through neighbourhood social capital. Furthermore, it is possible that neighbourhood social capital benefits chronic illness self-management in additional ways. For instance, increased emotional wellbeing in neighbourhoods with more social capital through feelings of safety and respect may help people with chronic illness to gain confidence and overcome barriers to self-management. The fifth study of this thesis will examine whether neighbourhood social capital, through the resources it provides, does indeed lead to better self-management as viewed from the perspective of people with chronic illness. The proposition that the neighbourhood can provide social resources to support self-management is based on the 'Network-episode model'. The 'Network-episode model' (Pescosolido, 1991) acknowledges that not only as a result of individual differences, but also because of the resources provided by social networks, people differ in their ability to adjust to the presence and consequences of a chronic illness. The 'Network-episode model' recognizes that networks and different social contexts are sources of information, beliefs, attitudes and knowledge about health and illness and provide resources to help manage a chronic illness. It is unlikely that resources generated in the neighbourhood are illness specific, and provide information that is relevant for specific medical tasks or complex medication regimes. However, neighbourhood resources might benefit the way people handle lifestyle adjustments, and the extent to which they succeed to integrate a chronic illness into the roles and responsibilities they fulfil in their daily life. The fifth study of this thesis will focus on the following non-disease specific aspects of self-management: whether people with chronic illness are able to deal with the effect of their condition on their physical activities, on their mental wellbeing, on their relationships with others and whether they succeed in maintaining a healthy lifestyle. This study will investigate whether neighbourhood social capital is related to self-management of people with chronic illness, and whether self-management is a mechanism behind the relationship between neighbourhood social capital and health.

The research question this study aims to answer is:

Does improved chronic illness self-management explain the relationship between neighbourhood social capital and health?

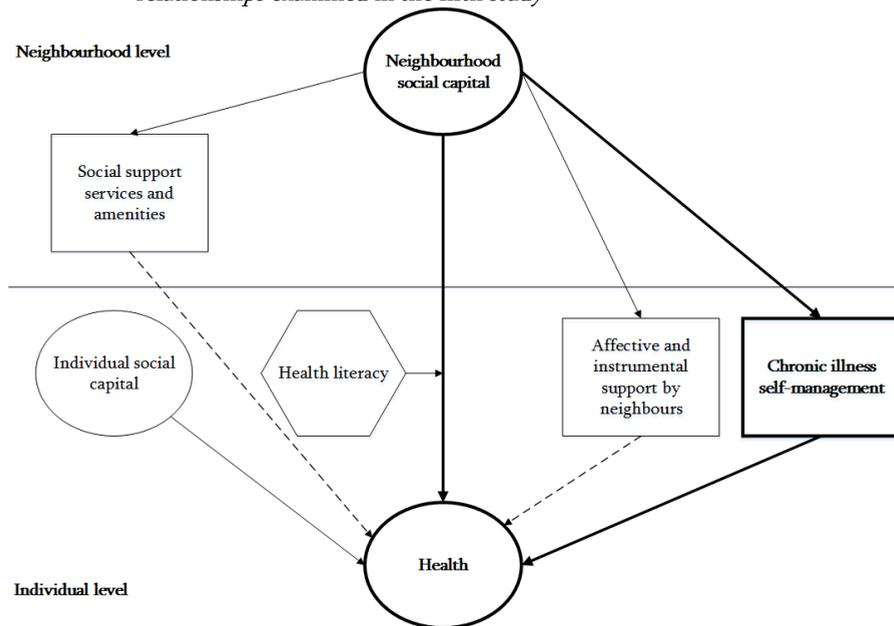
This study will test the following hypotheses:

Hypotheses:

1. There is a positive relationship between neighbourhood social capital and chronic illness self-management and between chronic illness self-management and health.
2. Chronic illness self-management (partly) explains the relationship between neighbourhood social capital and health.

The bold shapes in figure 1.5 identify the relationships that are examined in this study.

Figure 1.5 Conceptual model of the relationship between neighbourhood social capital and health and mechanisms behind this relationship, with emphasis on the relationships examined in the fifth study



Increased access to health information as a mechanism behind the relationship between neighbourhood social capital and health of people with chronic illness

People with chronic illness need to access, understand and apply health information to make decisions about health, for instance about the symptoms they experience, healthcare, medication or lifestyle changes. People with chronic illness in neighbourhoods with more social capital might be in better health because they have increased access to relevant health information (Kawachi et al., 1999; Kawachi et al., 2000). They might for instance receive information about healthy food outlets nearby or exercise groups that they can join. They might also hear about healthy recipes, supplements that might benefit their health or a good physical therapist that just opened up a practice. Connections between neighbours might provide access to different types of information, as exchange of information benefits from larger networks that are more dispersed and consist of weak ties (Cattell, 2001; Granovetter, 1973). The people with whom individuals have weak connections (e.g., people in their neighbourhood) are more likely to move in different circles and will thus have access to other sources of information.

Although increased access to health information is beneficial for all people with chronic illness, it might especially benefit those people with chronic illness that have difficulty gaining access to, understanding and applying health information due to low health literacy skills. By providing access to health information, neighbourhood social capital might compensate for a lack of health literacy skills. Health literacy refers to a broad range of characteristics and personal as well as social resources people need to access, understand, evaluate, and communicate information to make decisions about health (Beauchamp et al., 2015; Begoray and Kwan, 2012). Low health literacy may have adverse consequences on health by limiting patients' ability to comprehend health information and find the healthcare they need, for instance because they experience difficulty in communicating with healthcare professionals. Health literacy also includes information and decision-making skills that are needed in a range of different contexts, such as the supermarket where people choose their food and in social settings in which lifestyle is reinforced (Nutbeam, 2000; Osborne et al., 2013; Peerson and Saunders, 2009). It has been suggested that the negative impact of low health literacy can be buffered through the transmission of health information within social networks and communities (Lee et al., 2004). However, it is also possible that health literacy skills are needed to access and use

neighbourhood resources to promote health. Therefore neighbourhood social capital may especially benefit people with chronic illness if they have better health literacy skills. To date there are no studies investigating the beneficial effects of neighbourhood social capital for people with chronic illness with varying health literacy skills. The last study of this thesis examines whether neighbourhood social capital compensates for low health literacy skills by providing access to information, or whether health literacy skills enhance the effect of neighbourhood social capital. The research question this study aims to answer is:

Does the effect of neighbourhood social capital on health of people with chronic illness vary according to health literacy skills?

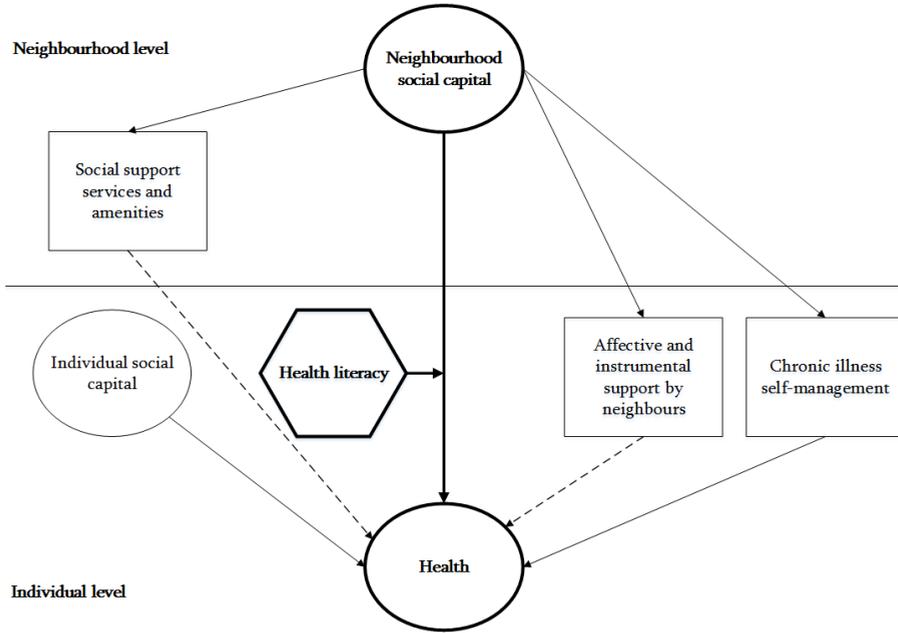
To discover whether neighbourhood social capital can benefit health of people with low health literacy skills through increased access to health information or whether health literacy skills enhance the effect of neighbourhood social capital, this study will test the following hypothesis:

Hypothesis:

There is an interaction between neighbourhood social capital and health literacy skills that has an effect on the health of people with chronic illness.

The bold shapes in figure 1.6 identify the relationships that are examined in this study.

Figure 1.6 Conceptual model of the relationship between neighbourhood social capital and health and mechanisms behind this relationship, with emphasis on the relationships examined in the sixth study



The neighbourhood

There are many different neighbourhood definitions in the literature. Neighbourhoods can, for instance, be defined spatially based on key area codes (Lochner et al., 2003), defined as zones around a home with a predefined radius, or designated more qualitatively by the individual perceptions that residents have of the area around their house (Wen et al., 2003). The challenge in unravelling neighbourhood effects, and more specifically the effect of neighbourhood social capital, is that we do not know the 'true' spatial context that influences individual behaviour. The scale on which to measure social capital is dependent on the mechanism that is studied. For the study in which we examine whether increased access to services and amenities is a mechanism behind neighbourhood social capital and health, we look at social capital on the municipal level. For the other studies in this thesis we examine social capital at the neighbourhood level by using the smallest possible unit of aggregation

available to us, namely 4-digit postal codes. Postal codes in the Netherlands are used to identify small geographical areas that comprise between 1-8 km². On average there are 4,000 residents in a postal code area (Statistics Netherlands, 2016). Literature based on neighbourhood effects which relies on the same area, namely postal codes in the Netherlands, presents evidence that neighbourhood social capital is related to individual health (Mohnen et al., 2011). It is possible that postal codes do not (always) reflect the boundaries of the neighbourhood as experienced by residents (Weaver, 2015). Duncan et al. (2014) suggest the use of egocentric neighbourhoods. Studies have found that self-defined neighbourhoods are different from, and often smaller than, commonly used neighbourhood boundaries such as a predefined radius around the house and census tract boundaries (Colabianchi et al., 2014; Coulton, 2012). However, using egocentric neighbourhoods and thus not defining the boundaries of neighbourhoods, we would not be able to study the effect of neighbourhood-level variables.

Data collection

To gain information on health and self-management of chronic illness for the studies in this thesis, we use data provided by members of the National Panel of people with Chronic illness or Disability (NPCD). This is a nationwide prospective panel study in The Netherlands, established to gather information on the consequences of chronic disease and disability from a patient perspective. Through the years the NPDC includes 3,500-4,000 people with a chronic disease or physical disability. For the NPCD, participants are recruited from random samples of general practices that are drawn from the Dutch Database of General Practices. They are selected according to the following criteria: diagnosis of a somatic chronic disease by a certified medical practitioner, aged >15 years, not permanently institutionalized, aware of the diagnosis, not terminally ill (life expectancy >6 months according to their general practitioner), mentally capable of participating, and sufficient mastery of Dutch. Members of NPCD are also recruited on the basis of a self-reported moderate or severe physical disability from several national population surveys conducted by the Netherlands Institute for Social Research, the Dutch Ministry of Infrastructure and the Environment and Statistics Netherlands. To avoid test effects, members participate for a maximum of four years. Annually, 500 new panel members are selected via a standardised procedure to replace drop-outs and members who reached the

maximum participation term. The NPCD is registered with the Dutch Data Protection Authority; all data are collected and handled in accordance with the privacy protection guidelines of this Authority. For the main part of this thesis, we analyse quantitative data collected by self-report questionnaires sent to members of the NPCD. We also want to gain more information about how people with chronic illness perceive the contributions of neighbours and other social network members to health and self-management. Therefore we conduct interviews with chronically ill members of the NPCD. These qualitative results will be used in the second study of this thesis.

Information about neighbourhood social capital is not derived from data provided by the sample of people with chronic illness that participate in the studies in this thesis. We will acquire information about neighbourhood social capital through WoOn, the 'Housing and Living Survey', commissioned by the Ministry of the Interior and Kingdom Relations. This approach provides an objective measure of the neighbourhood social context and enables a clear distinction between individual social capital of people with chronic illness and neighbourhood social capital. WoOn is representative of residents of the Netherlands of 18 years and above. Data for WoOn are collected by telephone, face to face interviews and internet. Participants are randomly selected from the population of Dutch households with at least one person aged 18 years or above. We use the postal code of the residential address of people with chronic illness to add the information on neighbourhood social capital to the datasets containing information provided by people with chronic illness.

Analyses

For the quantitative studies in this thesis multilevel regression analysis will be used to analyse the data. Multilevel analysis makes it possible to separately attribute variation in health to the neighbourhood level and to the individual level. The dependent variables in this thesis are self-rated health, the provision of services and amenities in municipalities and chronic illness self-management.

Self-rated health is assessed with the 'perceived general health' subscale from the RAND-36 short-form health status survey. In the RAND-36 survey respondents are asked to answer the question "In general how would you say your health is?" on a 5-point scale ranging from excellent to poor. Respondents then select

answers that best describe how much they agree with four statements about their health on a 5-point scale ranging from totally agree to totally disagree. The statements are “I seem to get sick a little easier than other people”, “I am as healthy as anybody I know”, “I expect my health to get worse,” and “My health is excellent.” (Van Der Zee and Sanderman, 1993).

The provision of services and amenities by municipalities is measured in three ways (Vonk et al., 2010). The first indicator is the number of services that municipalities provide to support informal caregivers. The second indicator is the number of different individual services and support that the municipality offers. The third indicator is the number of general and collective services and amenities that are available within municipalities.

Self-management is measured by a few items of the Partners in Health Scale (Battersby et al., 2003). The Partners in Health Scale has been shown to be a valid and consistent measure of patient self-management ability. As previously mentioned, we expect that the resources provided in neighbourhoods are relevant for the ability people have to cope with the general consequences of a chronic disease in their daily life. We expect that neighbourhood resources are less relevant for their interaction with medical professionals or for their ability to perform disease specific management tasks (such as adhering to complex medication regimes or monitoring blood sugar levels). Therefore we only use items that measure whether people can deal with the effect of their condition on their physical activities (such as walking, domestic chores), on their feelings (emotions and mental wellbeing), on their relationships, and whether they succeed in maintaining a healthy lifestyle.

The main explanatory variable on the neighbourhood level is neighbourhood social capital. Neighbourhood social capital is measured by five questions about contact among neighbours, namely:

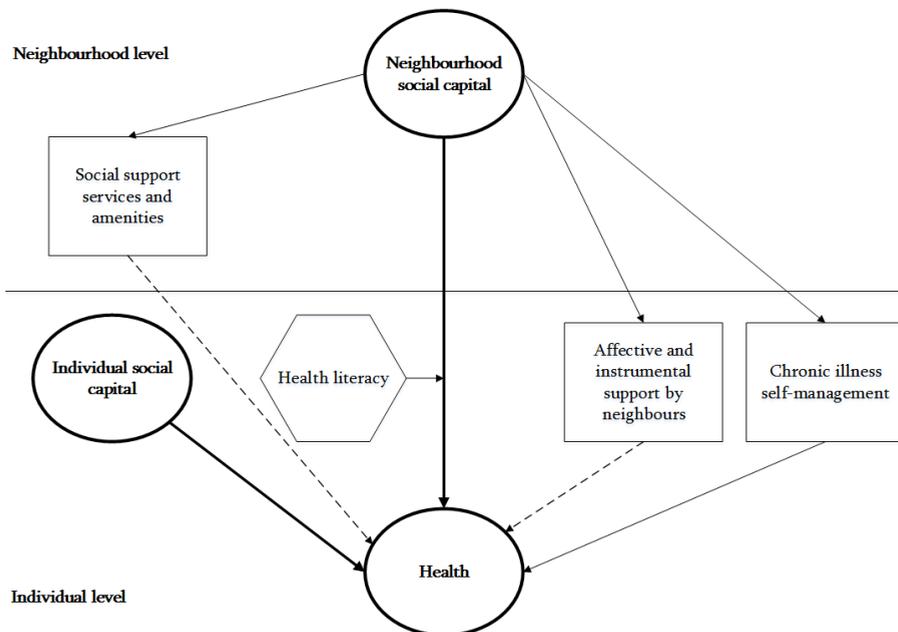
- contact with direct neighbours;
- contact with other neighbours;
- whether people in the neighbourhood know each other;
- whether neighbours are friendly to each other;
- whether there is a friendly and sociable atmosphere in the neighbourhood.

To generate a neighbourhood level variable from these individual responses, we apply econometric analysis, using a three-level hierarchical model (Raudenbush and Sampson, 1999; Raudenbush, 2003). The highest two levels of the model can

be viewed as a multivariate model for the latent true scores, with the lowest level serving as a measurement model (Raudenbush et al., 1991). By aggregating individual responses to the neighbourhood level by using the ecometric method, we adjust for differences in the number of respondents per neighbourhood. Furthermore, we adjust for differences between individuals within neighbourhoods by including sex, age, education, income, employment status, home ownership and years of residence. We also include the items that measure social capital, so that the model parameterizes the measurement error variation and takes into account item difficulty based on individual response patterns. Based on this ecometric model, variance can be partitioned into three components: variation among neighbourhoods, variation among individuals, and variation within individuals among items used for the social capital measure. We construct a social capital measure based on the variation among neighbourhoods.

2

A prospective analysis of the effect of neighbourhood and individual social capital on changes in self-rated health of people with chronic illness



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Abstract

Background Social capital in the living environment, both on the individual and neighbourhood level, is positively associated with people's self-rated health. However, prospective and longitudinal studies are rare, making causal conclusions difficult. To shed more light on the direction of the relationship between social capital and self-rated health, we investigated main and interaction effects of individual and neighbourhood social capital at baseline on changes in self-rated health of people with a somatic chronic disease.

Methods Individual social capital, self-rated health and other individual level variables were assessed among a nationwide sample of 1048 non-institutionalized people with a somatic chronic disease residing in 259 neighbourhoods in the Netherlands. The assessment of neighbourhood social capital was based on data from a nationwide survey among the general Dutch population. The association of social capital with changes in self-rated health was assessed by multilevel regression analysis.

Results Both individual social capital and neighbourhood social capital at baseline were significantly associated with changes in self-rated health over the time period of 2005 to 2008 while controlling for several disease characteristics, other individual level and neighbourhood level characteristics. No significant interactions were found between social capital on the individual and on the neighbourhood level.

Conclusions Higher levels of individual and neighbourhood social capital independently and positively affect changes in self-rated health of people with chronic illness. Although most of the variation in health is explained at the individual level, one's social environment should be considered as a possible relevant influence on the health of the chronically ill.

Background

Beyond characteristics of the individual, physical and social features of the environment are also related to variations in human health and disease (Diez Roux and Mair, 2010; Diez Roux, 2001; Lomas, 1998; Pickett and Pearl, 2001; Subramanian, Lochner, and Kawachi, 2003). This has sparked considerable interest in the association between neighbourhood context and health outcomes. An important neighbourhood characteristic is social capital. Social capital is rooted in social relations and grows through ties within networks, such as families, communities, or neighbourhoods. It works through shared norms and mutual trust, and it is a resource that is utilized by both individuals and groups. Social capital influences the behaviour of those within the social circle in which it operates. Unlike human capital, social capital cannot be seen as the 'possession' of an individual but rather as a supply of resources that exists within the structure of relations between actors (Coleman, 1988). People living in neighbourhoods with more social capital experience better health, independent of socio-demographic characteristics of the neighbourhood and physical characteristics of the residents (Kawachi, 1999; Linden-Bostrom et al., 2010; Lochner et al., 2003; Mohnen et al., 2011; Poortinga, 2006b; Snelgrove et al., 2009; Sundquist and Yang, 2007; Tampubolon et al., 2011; Wen et al., 2003).

Although there is evidence that neighbourhood social capital is an important contextual influence on health, it is unclear whether the effect of neighbourhood social capital differs according to the presence and severity of health problems. In this article we study the relationship between social capital and health specifically for people with chronic illness. We investigate changes in self-rated health over time in relation to social capital in neighbourhoods at baseline. Moreover, we study both collective and individual social capital. Collective social capital is located on the geographical level and is based on the level of social capital of the inhabitants of a neighbourhood.

The increasing prevalence of chronic illness in the population (Blokstra et al., 2007) calls for more insight into the factors that contribute to health and wellbeing. Most research concerning the health of people with chronic illness neglects the contextual effect of the social environment. The residential environment might be especially important when disabilities potentially limit the action space of people with chronic illness. Social capital can be seen as a

potential supportive resource that helps people cope with the consequences of their illness. It may also encourage them to engage in a lifestyle that prevents deterioration of health.

Current research on social capital and health is most often cross-sectional, which makes it difficult to establish the direction of the relationship between social capital and health. In most studies it cannot be ruled out that selection effects are responsible for the association between the neighbourhood environment and health. This means that we cannot exclude the possibility that people with better health are selected into certain neighbourhoods and that reverse causality might play a role, i.e. that good health is a determinant of social capital rather than the other way around. Neighbourhood characteristics (such as the level of deprivation, neighbourhood problems, and social capital) have been linked through prospective research to incidence of disease (Cubbin and Winkleby, 2005; Sundquist et al., 2006; Winkleby et al., 2007) functional disability and functional decline (Aida et al., 2013; Balfour and Kaplan, 2002; Poulsen et al., 2014), prevalence of mental disorders and mental hospitalization (Lofors and Sundquist, 2007; Stafford et al., 2008) and mortality rates (Blakely et al., 2006; Sundquist and Hamanoc, 2014; Winkleby et al., 2007; Wing et al., 2005). Murayama et al. (2012) in their review of prospective multilevel studies on social capital and health identify one prospective study about the effect of area level social capital on self-rated health, which shows that high individual and area social trust have a positive effect on self-rated health (Poortinga, 2006b). A study published after this review examined the effect of neighbourhood social capital on health among a sample of pregnant women in Brazil (Lamarca et al., 2013). With regard to the effect of social capital over time on the individual level it was found that frequent contact with neighbours is associated with better self-rated health over a period of two years (Giordano and Lindström, 2011; Giordano et al., 2012). It can be expected that people with chronic illness experience more pronounced health changes in shorter periods of time than the general population. Therefore, this population is especially suitable to study the effect of social capital (on both the individual and neighbourhood level) on changes in health.

Social capital has been conceptualized and measured both at the collective (e.g. neighbourhood) and individual level. Although there are mixed results on the strength of the association, both neighbourhood social capital (Kawachi, 1999;

Linden-Bostrom et al., 2010; Lochner et al., 2003; Mohnen et al., 2011; Poortinga, 2006b, Snelgrove et al., 2009; Sundquist et al., 2007; Tampubolon et al., 2011; Wen et al., 2003) and individual social capital (Giordano et al., 2011; Lindström, 2004; Veenstra, 2000) are positively related to self-rated health. Social capital on the individual level exists in relations between specific actors (Kawachi et al., 1997), while social capital on a geographical level is a collective and non-exclusive good that can also benefit those who do not personally invest in the social structure they belong to (Coleman, 1988). As such, people with less individual social capital, who seldom participate or invest in their neighbourhood, can potentially benefit from living in a high social capital community, e.g. because this community is a safe and welcoming environment in which to stay physically active. This might be important for people with chronic illness who might be less able to participate in their neighbourhood (and gain individual social capital) because of the limitations their health condition presents. Individual responses to survey questions about relationships in the neighbourhood can be used to construct a measure of collective social capital (Moore et al., 2006) through aggregation of responses or econometric analysis (Raudenbush and Sampson, 1999).

Interactions between collective and individual social capital have been reported (Carpiano, 2008; Elgar et al., 2011; Mohnen et al., 2015; Poortinga, 2006a). Results suggest that social capital on a geographical level does not uniformly benefit individuals in the same way. People with higher levels of trust and civic participation are more likely to report good health than people with low levels of trust and civic participation rates in countries with high levels of trust and civic participation rates. But this is not the case in countries with low levels of trust and civic participation rates. This means that in countries with high levels of social capital, people with high levels of individual social capital benefit more from this than people with a low level of individual social capital (Poortinga, 2006a). Furthermore, it was found that neighbourhood social capital can compensate for a lack of individual social capital (Mohnen et al., 2015). An accumulating effect might also occur if social ties at the individual level strengthen the relationship between neighbourhood level social capital and health (Carpiano, 2008).

This research aims to contribute to existing literature by examining the relationship between social capital, both on the individual and on the

neighbourhood level, and changes over time in self-rated health among people with a somatic chronic disease. We test the following hypotheses:

Hypotheses:

1. A higher level of individual or neighbourhood social capital exerts a positive influence on changes in the self-rated health of people with a medically diagnosed somatic chronic disease.
2. There is an interaction between the effect of neighbourhood social capital and individual social capital on changes in self-rated health.

Methods

Geographical unit

Neighbourhoods can be spatially defined based on key area code (Lochner et al., 2003), defined as quantitative administrative units (Linden-Bostrom et al., 2010) or more qualitatively designated by the individual perceptions that residents have of the area where they live (Wen et al., 2003). In our study neighbourhoods are spatially defined based on 4-digit postal codes. Postal codes in the Netherlands are used to identify relatively small geographical areas that comprise between 1–8 km² with an average of 1,800 households and 4,000 residents per postal code area (Statistics Netherlands (CBS), 2014). Due to differences in population density, neighbourhoods comprise relatively small areas in cities and larger areas in rural municipalities. In our study sample there are on average 4.0 chronically ill residents per neighbourhood (SD=6.7), in 259 urban and rural postal code areas.

Data

Three data sources were used to test our hypotheses. Two of these data sources contained information about the neighbourhood. The first dataset was the 'Housing and living survey 2006'(WoON) as previously used by Mohnen et al. (2011). This provided us with a measure of neighbourhood social capital, based on an average of 19 respondents per neighbourhood (Mohnen, 2012). The WoON survey data were collected among a representative sample of the general population under the authority of the former Ministry of Housing, Spatial Planning, and Environment. The WoON data provide an independent measure of social capital, established separately from the perceptions of the study sample

of people with chronic illness. In total, 6,4005 respondents participated in the WoON 2006 survey.

A second dataset containing neighbourhood control variables, based on aggregated register information, was provided by Statistics Netherlands and was added to these data (CBS, 2014).

The third dataset yields information on the individual level and was used to construct a measure of self-rated health and individual social capital. These data are based on longitudinal survey data from the 'Nationaal Panel Chronisch zieken en Gehandicaptten' (National Panel of the Chronically ill and Disabled or NPCD). This is a nationwide prospective panel in The Netherlands established to gather information on the consequences of chronic disease and disability from a patient perspective (Rijken and Groenewegen, 2008). For the NPCD, participants are recruited from random samples of general practices that are drawn from the Dutch Database of General Practices. For the present study, participants with a chronic disease were recruited from 44 different practices. They were selected using the following criteria: diagnosis of a somatic chronic disease by a certified medical practitioner, aged >15 years, not permanently institutionalized, aware of the diagnosis, not terminally ill (life expectancy >6 months according to their general practitioner), mentally capable of participating, and sufficient mastery of Dutch. Annually, 500 new panel members are selected via the standardized procedure to replace panel members who withdrew or who had participated for the maximum term of four years. All non-institutionalized people in The Netherlands are listed with a general practice and general practitioners keep lifelong patient files which are carried over in case a patient residentially relocates. NPCD is registered with the Dutch Data Protection Authority; all data are collected and handled in accordance with the privacy protection guidelines of this Authority. Panel members fill in questionnaires at home twice a year. The present study used panel data from 2005 to 2008. For the purpose of this study we confined our sample to respondents to the questionnaire of 2005 and from whom we had at least one additional assessment of self-rated health in later years as well as a baseline measure of individual social capital. In April 2005, a survey was sent to 2,164 panel members diagnosed with a chronic disease, for whom we possessed neighbourhood social capital information. A total of 1,914 people completed the questionnaire in 2005 (88%) and a total of 1,048 completed an additional questionnaire in the following years and provided information to

construct measures of self-rated health and individual social capital. Those who only filled out the questionnaire in 2005, and did not drop out before the next questionnaire because they had participated for a maximum of 4 years (this was the case for 29% of the people who participated in 2005) did not differ from those who did complete one of the next questionnaires in terms of age, education level, level of individual social capital, number of chronic illnesses, and the presence and severity of a disability. The people who filled out an additional questionnaire were a bit younger on average (57 versus 58 for those who did not participate in further measurements) and more often female (57% versus 52%), but these differences were not significant.

Measurements

Health change

Self-rated health in 2005 was used as baseline health. The dependent variable was derived from one to three measurements of respondents' self-rated health after 2005, as assessed with the scale 'general health' from the RAND-36 short-form health status survey (Van der Zee and Sanderman, 1993). In the RAND-36 survey respondents are asked to answer the following question: "In general how would you say your health is?" with answers on a 5-point scale, ranging from 'excellent' to 'poor'. Respondents then select answers that best describe how much they agree with four statements about their health on a 5-point scale ranging from 'totally agree' to 'totally disagree'. The statements are: "I seem to get sick a little easier than other people", "I am as healthy as anybody I know", "I expect my health to get worse" and "My health is excellent". The scale score of perceived general health is the sum of these five items, rescaled to range from 0 (worst health) to 100 (best health) (Van der Zee et al., 1993). A higher score reflects better self-rated health. In our study, Cronbach's alpha of the scale varied between 0.805 and 0.823 (depending on the measurement year), indicating a high internal consistency. This measurement instrument was found to have good discriminatory power among a sample of people with a chronic disease in Finland who were critically ill (Karlola et al., 2004). The correlation of this scale with objective health measures and physician-assessed health is high (Mossey and Shapiro, 1982; Simon et al., 2005). There are a maximum of four measurements of health for each respondent. All included respondents have the measurement of health at baseline in 2005 (independent variable). There are 959 respondents who have a measurement of health in 2006, 878 respondents who have a measurement of health in 2007, and 702 respondents who have a

measurement of health in 2008. There are 625 respondents who have three additional measurements of health (after baseline measurement), 241 respondents who have two additional measurements of health, and 182 respondents who have one additional measurement of health. Because people participate in the NPCD for a maximum of four years, people who received their first questionnaire before 2005 or before 2004 were unable to participate after the measurement in 2007 and after the measurement of 2006 respectively.

Individual social capital

Individual social capital in the neighbourhood was derived from ten items from the NPCD questionnaire in 2005, which include: 'I like the neighbourhood where I live', 'I feel connected to this neighbourhood', 'I know my neighbours well' and 'There is social interaction in this neighbourhood'. These questions are based on the items used to assess neighbourhood social capital in the 'Housing needs survey 2002' which was conducted under the authority of the former Ministry of Housing, Spatial Planning, and Environment. Respondents were asked to choose their level of agreement with these statements on a 5-point scale ranging from 'totally disagree' to 'totally agree'. The scale score of individual social capital was a sum of these ten items, ranging from 10–50, with a higher score indicating higher levels of individual social capital in the neighbourhood. The reliability of this scale in our study was high (Cronbach's alpha=0.935).

Individual level control variables

Among the individual level variables are a number of demographic and illness characteristics, namely: sex, coded as a dummy variable; age, measured in years in 2005; educational attainment, coded as either low (no education until the lowest high school degree), average (vocational training and the highest two high school degrees), or high (university of applied sciences degree and university degree); net equivalent income in four categories (less than 900 euro, 900–1,200 euro, 1,200–1,600 euro, more than 1,600 euro). Net equivalent income is defined as the sum of the monthly net incomes (regardless of source) of all household members corrected for household composition (Siermann et al., 2004). We also included employment status (having a paid job or not) and marital status (being married or not). Three disease characteristics were included: the nature of the first diagnosed disease (including cardiovascular diseases, cancer, respiratory diseases, diabetes, musculoskeletal diseases, neurological diseases and digestive diseases); the number of chronic diseases (ranging from 1 to '3 or more') as

reported by the general practitioner; and self-reported severity of the disability (no disability or mild disability, moderate disability, severe disability), as assessed by a validated Dutch questionnaire containing questions about the ability to perform a number of activities in daily life (De Klerk et al. 2006). Descriptive statistics of individual level variables are presented in table 2.1.

Table 2.1 Descriptive statistics of individual variables of chronically ill (n=1048)

| | Range | Mean | S.D. | Percent |
|--|--------|------|------|---------|
| <i>Health 2005</i> | 0-100 | 53.9 | 20.7 | |
| <i>Health 2006</i> | 0-100 | 53.4 | 20.8 | |
| <i>Health 2007</i> | 0-100 | 54.5 | 21.8 | |
| <i>Health 2008</i> | 0-100 | 53.0 | 21.7 | |
| <i>Change in health 2006–2008 vs. 2005</i> | –55/60 | 11.4 | 14.9 | |
| <i>Sex:</i> | | | | 43.3 |
| male | | | | 56.7 |
| female | | | | |
| <i>Age in years</i> | 16-95 | 56.9 | 15.0 | |
| <i>Education:</i> | | | | |
| low | | | | 56.3 |
| middle | | | | 25.3 |
| high | | | | 18.4 |
| <i>Income:</i> | | | | |
| less than €900 | | | | 11.0 |
| €900–€1200 | | | | 21.2 |
| €1200–€1600 | | | | 18.9 |
| more than €1600 | | | | 16.6 |
| unknown | | | | 32.3 |
| <i>First diagnosed chronic disease:</i> | | | | |
| Cardiovascular disease | | | | 10.4 |
| cancer | | | | 2.8 |
| respiratory disease | | | | 42.6 |
| diabetes | | | | 11.9 |
| musculoskeletal disease | | | | 9.5 |
| neurological disease | | | | 5.5 |
| digestive disease | | | | 3.4 |
| unspecified other disease | | | | 13.9 |
| <i>Number of chronic diseases:</i> | | | | |
| one | | | | 71.3 |
| two | | | | 20.3 |
| three or more | | | | 8.4 |

- table 2.1 continues -

-table 2.1 continued -

| | | | |
|--|-------|------|------|
| <i>Number of chronic diseases:</i> | | | |
| one | | | 71.3 |
| two | | | 20.3 |
| three or more | | | 8.4 |
| <i>Severity of disability:</i> | | | |
| none or mild disability | | | 70.3 |
| moderate disability | | | 22.0 |
| severe disability | | | 7.7 |
| <i>Marital status:</i> | | | |
| unmarried | | | 33.6 |
| married | | | 66.5 |
| <i>Employment status:</i> | | | |
| unemployed | | | 58.6 |
| employed | | | 40.0 |
| unknown | | | 1.4 |
| <i>Individual level social capital</i> | 10-50 | 38.6 | 7.4 |

Neighbourhood social capital

Social capital is rooted within ties between individuals and through these ties resources are created. Therefore social capital is measured by specifically focusing on contacts between neighbours. ‘Neighbourhood social capital’ was assessed by five questions relating to contact among neighbours. Items address the following: contact with direct neighbours, contact with other neighbours, whether people in the neighbourhood know each other, whether neighbours are friendly to each other and whether there is a friendly and sociable atmosphere in the neighbourhood. Respondents were asked to choose their level of agreement with these statements on a 5-point scale ranging from ‘totally disagree’ to ‘totally agree’. An econometric analysis was used to create the measure of neighbourhood social capital (as previously described by Mohnen et al. (2011)). The econometric approach accounts for the dependency among the items that measure social capital, for different numbers of respondents in neighbourhoods and is adjusted for individual characteristics of the respondents. Neighbourhood level residuals are used to indicate neighbourhood social capital.

Neighbourhood control variables

Urbanity of the municipality and neighbourhood income were used as control variables at the neighbourhood level. The level of urbanity was based on a 5-point scale: rural, semi-rural, intermediate urban–rural, semi-urban, strongly

urban. Income was assessed by the percentage of people in the highest income quintile in a neighbourhood. We aimed to control for ethnic diversity of a neighbourhood by including the percentage of immigrants, but as a consequence of its high correlation with the level of urbanity (correlation coefficient of 0.82), it was omitted from the analyses. Models run with ethnic diversity included instead of the level of urbanity did not differ significantly in the effect of our main outcome variables from models with the level of urbanity included instead of ethnic diversity. Table 2.2 shows the descriptive statistics of neighbourhood level variables.

Table 2.2 Descriptive statistics of neighbourhood characteristics (n=259)

| | Data source | Year | Range | Mean | SD |
|---|-------------------------|------|-----------|-------|------|
| Urbanity of municipality | Stat. Neth ^a | 2005 | 1-5 | 2.9 | 1.3 |
| Percentage of population in the highest income quintile | Stat. Neth | 2005 | 1.9-28.5% | 14.4 | 5.0 |
| Percentage of immigrants | Stat. Neth | 2006 | 0-89.7% | 15.8 | 12.3 |
| Neighbourhood social capital* | WoON | 2006 | -2.8-2.0 | -0.22 | 0.83 |

* Based on Mohnen et al. (2011)

^a Stat. Neth=Statistics Netherlands

Analytic strategy

The data were analysed by performing multilevel linear regression analyses, using Stata and MLwiN 2.24. We ran MLwiN through Stata using the ‘runmlwin’ Stata command. A three-level model (neighbourhoods, individuals, measurements) was used. This accounts for the nesting of measurements of self-rated health within individuals and individuals within neighbourhoods. We assume that the random effects are normally distributed. We specified a full variance/covariance structure between measurement occasions at level 2 in order to account for the correlation of measurements within individuals. The correlation of measurements indicates the dependency between the measurements of self-rated health. We assume there are differences between individuals in the effect of time on self-rated health; the variances and covariances of the outcome variable are variable over time and dependent on position and spacing, because the correlation is larger between nearby measurements of health than between measurements that are further apart (measurements that are one year apart are more similar than measurements of health that are further apart). Furthermore, the effect of time might differ between individuals with different health conditions as some people may

experience a more stable health or faster deterioration than others. Snijders and Bosker (2012) call this a ‘fully multivariate model’ where the measurements for individuals are random at level two. This model does not have a random part at level one (Snijders et al., 2012). A description of the multilevel model used in this study can be found in the section ‘Additional Materials’.

We estimated an empty model (Model 0) to establish the clustering of health changes in a neighbourhood by controlling for baseline health in 2005 and differences caused by the time of measurement. Models 1 to 3 are estimated to test the first hypothesis: *A higher level of individual or neighbourhood social capital exerts a positive influence on changes in the self-rated health of people with a medically diagnosed somatic chronic disease.*

Model 1 includes variables on the individual level (including individual social capital). Model 2 adds neighbourhood social capital. Model 3 adds the neighbourhood control variables: the urbanity of the municipality and the percentage of people in the highest income quintile. In Model 4, the interaction between neighbourhood social capital and individual social capital is added to test the second hypothesis: *There is an interaction between the effect of neighbourhood social capital and individual social capital on changes in self-rated health.* Because there are only small changes in coefficients (and no significant changes) between the four different models, only the first model (the empty model) and the fifth model (the full model) are reported.

Results

Table 2.3 includes correlations between individual level variables. The presence and severity of a physical disability correlates most highly with self-rated health.

Table 2.4 shows correlations between neighbourhood level variables. The percentage of immigrants within a neighbourhood correlates highly with the urbanity of the area (>0.8); in more rural areas the percentage of immigrants decreases strongly. As mentioned previously, the percentage of immigrants is therefore not included in the analysis.

Table 2.3 Correlation between individual characteristics, self-rated health at baseline and individual social capital at baseline (at baseline: 2005)

| N _j =1048 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|--|-----------|-----------|-----------|-----------|------------|------------|-----------|----------|-------|------|
| 1. Health in 2005 | 1.00 | -- | -- | -- | -- | -- | -- | -- | | |
| 2. Gender ^a 0=male | -0.037* | 1.00 | -- | -- | -- | -- | -- | -- | | |
| 3. Age | -0.107*** | -0.138*** | 1.00 | -- | -- | -- | -- | -- | | |
| 4. Education level | 0.121*** | -0.096*** | -0.321*** | 1.00 | -- | -- | -- | -- | | |
| 5. Income | 0.116*** | -0.070** | -0.082*** | 0.385*** | 1.00 | -- | -- | -- | | |
| 6. Severity of disability | -0.455*** | 0.092*** | 0.290*** | -0.201*** | -0.150*** | 1.00 | -- | -- | | |
| 7. Number of chronic diseases | -0.169*** | 0.030 | 0.176*** | -0.067*** | -0.232*** | 0.157*** | 1.00 | -- | | |
| 8. Individual social capital | 0.079*** | -0.003 | 0.071*** | -0.036* | -0.014 | -0.085*** | -0.013 | 1.00 | | |
| 9. Employment status ^a (0=unemployed) | 0.210*** | -0.026 | -0.661*** | 0.285*** | 0.165*** | -0.333*** | -0.152*** | 0.014 | 1.00 | |
| 10. Marital status ^a (0=unmarried) | 0.033*** | -0.162*** | 0.035 | -0.064*** | -0.0618*** | -0.0723*** | -0.057** | 0.135*** | 0.028 | 1.00 |

N_j=Number of individuals

* p≤0.05, ** p≤0.01, *** p≤0.001

^a dichotomous variable

Table 2.4 Correlation between neighbourhood characteristics and neighbourhood social capital

| N _k =259 | 1 | 2 | 3 | 4 |
|---------------------------------|-----------|----------|----------|------|
| 1. Neighbourhood social capital | 1.00 | -- | -- | |
| 2. Urbanity of municipality | -0.512*** | 1.00 | -- | |
| 3. Highest income quintile | -0.108*** | 0.024 | 1.00 | |
| 4. Percentage of immigrants | -0.597*** | 0.816*** | 0.0530** | 1.00 |

N_k=Number of neighbourhoods

* p<0.05, ** p<0.01, *** p<0.001

The study sample consists of 1048 individuals within 259 postal code areas. The average score of self-rated health in 2005 was 53.93 and 53.03 in 2008. Twenty-nine percent of the respondents experienced a deterioration in health between the first year and last year of participation, 43% of the respondents did not experience any health changes and 27% of the respondents reported an improvement in self-rated health. A change in health of half a standard deviation or less (7 points on a scale of 0–100) was considered stable health (Norman et al., 2003).

There are only slight differences between neighbourhoods with regard to health changes of their chronically ill population. In the empty model (that includes self-rated health at baseline, see table 2.5), neighbourhood level variance of health changes was not significant (2.23, se=2.29).

The full model (table 2.5) shows that individual social capital is significantly associated with changes in respondents' self-rated health. Greater individual social capital at baseline is positively related to better self-rated health in later years. The same holds true for being married. Having a low income (a net equivalent income of less than 900 euros a month) as opposed to having a high income (a net equivalent income of more than 1,600 euros a month) is negatively related to self-rated health. Having severe physical disabilities as opposed to light or moderate disabilities is also negatively related to self-rated health. Neighbourhood level variance is reduced to half the variance of the empty model when individual variables are added to Model 1 (not shown in table). This indicates that composition effects play a role in the differences in health between neighbourhoods. Variances of the different measurements of health and the covariance between them are also reduced slightly (compared to the empty model) when individual variables are added to Model 1 (not shown in table).

Beyond individual characteristics (such as individual social capital, income, marital status, and disease characteristics), a higher level of neighbourhood social

capital at baseline positively relates to changes in individual self-rated health. When social capital is added in Model 2, remaining variance on the neighbourhood level is reduced to zero (not shown in table). The effect of neighbourhood social capital persists in the presence of other neighbourhood level variables. The percentage of people in the highest income quintile in a neighbourhood and the level of urbanity are not significantly related to changes in self-rated health of people with chronic illness. There is no significant interaction between neighbourhood social capital and individual social capital. Neighbourhood social capital and individual level social capital both independently impact changes in individual self-rated health.

Table 2.5 Multilevel regression models of individual and neighbourhood social capital on self-rated health in 2006, 2007, 2008 (Coefficients, 95% confidence intervals in parentheses)

| | Empty model (model 0) | Full model |
|-------------------------------------|-----------------------|-----------------------|
| <i>Intercept</i> (se) | 53.16 (0.54)*** | 44.61 (2.90)*** |
| <i>Measurement level:</i> | | |
| Time of measurement (ref=2008) | 0.21 (0.83,1.25) | 0.18 (-0.86,1.22) |
| 2006 | 1.19 (0.23,2.16)* | 1.17 (0.20,2.15)*** |
| 2007 | | |
| <i>Individual level:</i> | | |
| Health in 2005 | 0.77 (0.74,0.81)*** | 0.70 (0.66,0.74)*** |
| Gender: | | -0.26 (-1.79,1.26) |
| women | | |
| Age in 2005 | | -0.06 (-0.13,0.01) |
| Education (Ref=High): | | |
| low | | -0.08 (-2.16,1.99) |
| average | | -0.65 (-2.87/1.56) |
| Income (Ref=More than €1,600): | | |
| less than €900 | | -3.85 (-6.71/-0.99)** |
| €900-€1,200 | | -0.45 (-2.92,2.02) |
| €1,200-€1,600 | | -1.10 (-3.50,1.31) |
| unknown | | -2.12 (-4.88,0.63) |
| Marital state (Ref=unmarried): | | |
| married | | 1.56 (-0.03,3.16)* |
| Employment status (Ref=unemployed): | | |
| employed | | 1.30 (-0.67,3.27) |

- table 2.5 continues -

-table 2.5 continued -

| | Empty model (model 0) | Full model |
|---|-----------------------|---------------------|
| Severity of disability (Ref=severe): | | 6.82 (3.76,9.89)*** |
| no or mild disability | | 2.70 (-0.35,5.75) |
| moderate disability | | |
| Number of chronic diseases (Ref=three or more): | | |
| one disease | 1.19 | (-1.56,3.94) |
| two diseases | 1.02 | (-1.96,3.99) |
| Individual social capital in 2005 | 0.14 | (0.04,0.25)** |
| First diagnosed disease(ref=cardiovascular disease): | | |
| cancer | -0.30 | (-5.05,4.45) |
| respiratory disease | 0.84 | (-2.08,3.76) |
| diabetes | 1.11 | (-1.94,4.16) |
| musculoskeletal disease | 2.06 | (-1.18,5.30) |
| neurological disease | 0.91 | (-2.89,4.71) |
| digestive disease | 0.59 | (-3.95,5.14) |
| unspecified other disease | 3.60 | (0.58,6.63)* |
| Interaction neighbourhood social capital * individual social capital | 0.01 | (-0.11,0.13) |
| <i>Neighbourhood level:</i> | | |
| Neighbourhood social capital in 2006 | 1.03 | (0.00,2.06)* |
| Highest income quintile | -0.12 | (-0.27,0.02) |
| Urbanity of municipality | 0.15 | (-0.50,0.80) |
| <i>Measurements variance and covariance:</i> | | |
| Variance neighbourhood level (se) | 2.23 (2.29) | 0 (0) |
| Variance 2006 (se) | 186.31 (8.72) | 179.52 (8.23) |
| Variance 2007 (se) | 205.65 (9.99) | 190.74 (9.12) |
| Variance 2008 (se) | 206.07 (11.03) | 194.97 (10.32) |
| Covariance (2006, 2007) | 94.08 (7.56) | 83.75 (6.91) |
| Covariance (2006, 2008) | 91.48 (8.01) | 82.86 (7.45) |
| Covariance (2007, 2008) | 116.33 (8.65) | 103.37 (7.88) |
| <i>Intraclass correlation (%)^a</i> | 0.6 | 0 |
| <i>Correlations between measurements:</i> | | |
| Correlation (2006, 2007) | 0.48 (0.03) | 0.45 (0.03) |
| Correlation (2006, 2008) | 0.47 (0.03) | 0.44 (0.03) |
| Correlation (2007, 2008) | 0.57 (0.03) | 0.54 (0.03) |

* p≤0.05, ** p≤0.01, *** p≤0.001

^a Intraclass correlation=neighbourhood variation/(neighbourhood variation + mean individual variation of the three measurement moments). Mean individual variation=(variance + 2*covariance)/3

Discussion

Consistent with our first hypothesis we found that individual as well as neighbourhood social capital at baseline exert a significant positive effect on changes in the self-rated health of people with chronic illness. This means that people with chronic illness are less likely to experience deteriorating health when they possess higher levels of individual social capital at baseline or live in a neighbourhood with more social capital. This finding is consistent with cross-sectional studies in the general population where beneficial effects of individual and neighbourhood social capital on health were found (Giordano et al., 2011, Linden-Bostrom et al., 2010; Lindström, 2004; Lochner et al., 2003; Mohnen et al., 2011; Poortinga, 2006b, Snelgrove et al., 2009; Sundquist et al., 2007; Tampubolon et al., 2011; Veenstra, 2000; Wen et al., 2003). Our study adds two elements: First, our study population consists of people with a medically diagnosed chronic disease. The residential neighbourhood might be especially important for people with a chronic illness, as fewer of them have a paid job (Rijken et al., 2013) and might be more dependent on their immediate living environment as a consequence of disabilities. Second, our study has a prospective design relating baseline social capital to changes in health.

Although neighbourhood social capital influences changes in the health of people with a chronic illness, the major part of the variation in health changes is located at the individual level and is explained by individual factors. Our study sample is too small to be able to estimate significant neighbourhood variation. In general, the literature shows that neighbourhood variation in health and effects of neighbourhood characteristics are relatively small (Giordano et al., 2013; Lindström et al., 2004; Lochner et al., 2003; Snelgrove et al., 2009). More substantively, next to the neighbourhood, other sources of social capital, such as the family or workplace, might also be responsible for variations in health (Oksanen et al., 2008; Suzuki et al., 2010). The effect of neighbourhood social capital might also differ according to the level of one's exposure to it (Mohnen et al., 2011). In order to shed more light on the influence of social capital on health it is therefore relevant to study how different sources of social capital influence people who are variably exposed to those contexts.

Inconsistent with our second hypothesis we found that the effect of neighbourhood social capital does not interact with the amount of individual social capital people possess. This suggests that social capital in the neighbour-

hood influences people's self-rated health, independent of their own relations with neighbours and their own perception of the neighbourhood. The advantage of looking at individual social capital is that it is not necessarily confined to relationships within an administrative neighbourhood; it does more justice to the individual perception of what people consider to be their neighbourhood. Two fifths of the people with chronic illness in our sample report a relatively stable health. Adapting to the challenges brought about by a chronic illness might also involve the changing of internal standards about what is considered 'good health'. It is possible that a response shift occurs because people maintain a fairly stable conception of their health over time (Sprangers and Schwartz, 1999). In a sample of nonagenarians comparable rates of change of self-rated health were found (Galenkamp et al., 2013). Self-rated health in this sample turned out to be sensitive to changes in the number of chronic conditions and functioning; however, we cannot exclude the possibility that social capital affects people's adaptation of their perception of health rather than their actual health status.

Strengths and limitations

We cannot control for residential relocation of the respondents in the years after baseline measurement of self-rated health and social capital because previous address in case of relocation is not recorded. On average, 10% of the Dutch population moves each year. In 2006, the majority of people who moved, moved within their own municipality (60%), which could also be within their own neighbourhood (Statistics Netherlands (CBS), 2014). The average age of our sample was 56. Among the general population, people over 50 move significantly less (6% per year) than the average within the general population. Therefore, residential relocation might have influenced our results, but not in a strong way.

We lack data of those whose health so strongly deteriorated that they were unable to participate in future waves of the panel and those who were admitted to a nursing home. Between 2005 and 2008 approximately 15% of the attrition rate within the NPCD was caused by inability to further participate due to strongly deteriorating health, admission to a nursing home, or death. In our sample the reason of attrition (due to a strongly deteriorating health, admission to a nursing home, death or otherwise) was not related to baseline neighbourhood social capital. From the point of view of methodological bias, this is reassuring; however, it begs the question of the importance of social capital for

other health related outcomes, such as the ability to live independently and mortality.

We also lack information about the panel members' health in the years before entering the panel. Time since diagnosis varies (Kaarlola et al., 2004) because the aim of NPCD is to provide information about a representative cross-section of the Dutch population of people with chronic illness. We therefore have no insight into the progression of their health (and the level of social capital) before 2005. Studying the effect of social capital on health from the onset of the disease onwards or from the moment people become residents of a neighbourhood might clarify the patterns of health development over time.

The most important strength of this study lies in its prospective design. The cross-sectional nature of previous studies renders it difficult to draw causal inferences and evidence regarding the connection between neighbourhood social capital and the progression of health has to date been lacking. This study used a representative sample of people medically diagnosed with a somatic chronic disease. It is expected that their condition causes individuals with chronic illness to experience more pronounced health changes in shorter periods of time than people from the general population, which enhanced our ability to detect the influence of social capital on health over time. This study provides evidence that the residential environment contributes to changes in the self-rated health of people with a chronic disease.

The assessment of neighbourhood social capital was derived from a representative sample of residents from neighbourhoods and not from the sample of individuals with chronic illness participating in this study. This approach enables a clear distinction between the assessment of individual social capital and neighbourhood social capital and provides an objective measure of the neighbourhood social context. The fact that neighbourhood social capital was derived from a different dataset and was constructed through econometric analysis means that we cannot directly compare the coefficients of individual level social capital and neighbourhood social capital. This limits a causal interpretation of the relationship between individual social capital and neighbourhood social capital.

Conclusion

Besides individual social capital, social capital on the neighbourhood level is a possible relevant influence on the health of people with chronically illness; however, there is little clarity on the mechanisms behind this relationship and the importance of the neighbourhood with regard to the promotion of health for people with chronic illness. Future studies should focus on the mechanisms underlying the relationship between health and social capital, on the individual as well as the neighbourhood level, as well as on the differences in this respect between the general population and people with a chronic illness. The nature of pathways as well as their importance might differ between both population groups. Social support might be very important for people with a chronic illness. Influenced by norms that are operative within the neighbourhood, people with chronic illness might feel more motivated to perform healthy behaviours. In the case of physical activity e.g., this might be less intensive than in the general population, but still preventative of further deterioration of health. Contacts in the neighbourhood can facilitate the diffusion of health-related norms and information (Kawachi et al., 1999). A higher level of social capital might also create an impetus to undertake collective action on the basis of mutual trust and willingness to intervene for the common good. Through higher levels of social capital, residents might be able to lobby for better services and health-promoting amenities in the neighbourhood. Furthermore, social capital can influence mental health through a positive atmosphere of mutual recognition and respect (Kawachi et al., 1999).

Current policy of the Dutch government in the area of support and long-term care is to devolve responsibility to municipalities and to people themselves and their social networks. People with support needs will be stimulated to utilize their social network and neighbourhood resources before appealing to municipal services (Hoff et al., 2013). An important assumption in this policy is that people indeed possess a social network and live in neighbourhoods that are able and willing to provide needed support. Another assumption is that this policy does not lead to increasing inequalities between people with differing levels of access to support. Studies on the working mechanisms of individual and neighbourhood social capital play an important role in this (Eriksson, 2011). While assessing these policy changes, it is important to study a broader range of effects, e.g. whether people are able to live independently for a longer time in communities

with more social capital. Furthermore, it is also important to not only examine changes in health but also changes in social capital in order to discover how developments in the social environment influence health over time. Investigating the effect of neighbourhood social capital on the progression of health, and the mechanisms underlying this effect, provides a useful framework with which to identify what constitutes a health-supporting living environment (Eriksson, 2011).

Additional materials

Description of the multilevel repeated measures used in this study

$$Y_{tij} = \beta_0 + \beta_t x_t + \beta_i x_{0ij} + \beta_j z_j + v_j + U_{ti}$$

t=time 2006 .. 2008

i=individual 1 ..1048

j=neighbourhood 1 .. 259

Y_{tij} outcome score at moment (t) for an individual (i) in neighbourhood (j)

β_0 intercept

$\beta_t x_t$ deviation (β_t) from intercept for time (x_t)

$\beta_i x_{0ij}$ effect for variables measured at the individual level that are constant over time

$\beta_j z_j$ effect for neighbourhood variables that are constant over time

v_j random effect, the between neighbourhood variance

U_{ti} random effect, complete time dependent between and within individual

variance/covariance matrix $\begin{pmatrix} \sigma_{2006} & \sigma_{2006,2007} & \sigma_{2006,2008} \\ \sigma_{2006,2007} & \sigma_{2007} & \sigma_{2007,2008} \\ \sigma_{2006,2008} & \sigma_{2007,2008} & \sigma_{2008} \end{pmatrix}$

on the diagonal we have the within individual yearly (error) variance and off the diagonal the between individual covariance between two years.

All parameters of this matrix are estimated from the data and are unstructured, meaning they can all be different. All the random effects are assumed to be normally distributed.

Note that this variance/covariance matrix is modelled at the level of the individuals, the lowest level, the individual measurements, is empty.

3

Support by neighbours for people with chronic illness:
its place in people's overall support system

Abstract

Background The burden of chronic disease is rapidly increasing worldwide. To manage the demand on healthcare there is increasing focus on the support the social network can provide for people with chronic illness. The aim of this exploratory study was to gain insight in the contributions of social network members outside the nuclear family, among whom are neighbours, to self-management of people with chronic illness. Furthermore, this study aimed to gain insight into the barriers people with chronic illness experience to ask and receive support from their social network.

Methods We conducted ten semi-structured individual interviews with people with chronic illness. We used visual diagrams to gain insight into the contributions of specific social network members. Audio recordings of the interviews were analysed qualitatively by a thematic analysis approach.

Results Neighbours mainly provide support by helping practically in and around the home. The support provided by neighbours is mostly limited to occasional help and has clear boundaries. Respondents indicate that they do not want to interact with their neighbours too frequently. Friends are mainly valued for their emotional support for self-management, which differentiates them from neighbours. Children are also mainly valued for their emotional support. Partners are the main caregivers and facilitate independent living by taking on new responsibilities in the relationship when this is necessary.

However, people with chronic illness may lack the support they need because social network members live far away, or are busy with a paid job and raising their children. The respondents state that they are hesitant to ask and receive support from their social network, because it is difficult for them to become dependent on others. Respondents want to maintain reciprocity in their relationships with others and they have different strategies to safeguard the reciprocal nature of relationships.

Conclusion To help people with chronic illness who lack social network support, it is relevant to study how wider social contexts can contribute to health and self-management. Health promoting resources in neighbourhoods might benefit those who lack adequate support to help them overcome limitations to self-management and healthy behaviour. Furthermore, more research is needed to shed more light on the feasibility of the substitution of professional care and support by social network support.

Background

Partly as a result of population ageing, the burden of chronic diseases is rapidly increasing worldwide. To manage the resulting demand on healthcare and contain costs, there is increasing emphasis on the capability of people with chronic illness to take responsibility for the management of their disease. The onset of a chronic disease presents patients with a wide range of new tasks. They have to deal with the symptoms of their condition and possibly complex medication regimes. They might also have to exercise or adjust their diet. At the same time they might have to cope with the emotional consequences of their disease and the impact of their disease on their relationships with others. Furthermore, they have to integrate chronic disease care into the roles and responsibilities they fulfil in their daily life, and find new ways of attaining their goals whilst taking into account the constraints and limitations their disease places on them (Barlow et al., 2002; Glasgow et al., 2003). All these tasks can be referred to as self-management.

With regard to self-management tasks, Corbin and Strauss (1985) differentiate between illness related work (medical self-management tasks such as taking blood pressure), biographical work (work that is related to coming to terms with the effect of a chronic illness on social interaction with others and one's self-identity) and everyday life work (practical everyday tasks such as housekeeping, raising children, or a paid job). Self-management tasks can vary from routine to emergency. Whereas taking medications is a routine task, a COPD exacerbation or an insulin shock require emergency work. The work that needs to be performed each day can vary in amount, degree of difficulty, and time it takes. Domestic work might only be done once a week, but taking medication might happen three times a day, and physical exercise might be performed twice a week.

If social, cognitive, and physical functioning are not sufficient to manage an illness and maintain a satisfactory quality of life, people with chronic illness might be in need of self-management support. Healthcare providers can provide support for people with chronic illness, for instance by providing information about their symptoms, medication and treatment options; by helping patients to feel confident about symptom management; and by encouraging them to make choices that lead to improved health-outcomes (Bodenheimer et al., 2006; Dwarswaard et al., 2016; Glasgow et al., 2003; Wagner et al., 2001).

The largest part of chronic illness self-management takes place outside the healthcare setting. Tasks such as household work, gardening, groceries shopping, symptom monitoring and taking care of one's diet all take place in and around the home. To manage a disease outside the healthcare setting, people with chronic illness have to establish new work patterns. Corbin and Strauss (1985) define the division of labour, deciding what tasks need to be done and by whom, as a key question in relation to chronic illness-self management. The division of labour is especially relevant if people with chronic illness are incapable of independently fulfilling the tasks their chronic illness presents them with. Research has shown that the social network can contribute to chronic illness self-management in various ways (Dwarswaard et al., 2016; Furler et al., 2008; Vassilev et al., 2013). Social network members can for instance provide support for symptom monitoring, provide medication reminders, do groceries, help someone with physical exercise, go to healthcare appointments, assist with domestic work, help with personal care or transportation, and provide emotional support, information and advice (De Boer and De Klerk, 2013; De Klerk et al., 2014; Dwarswaard et al., 2016; Graven and Grant, 2014; Rosland and Piette, 2010; Strom and Egede, 2012; Vassilev et al., 2013; Vassilev et al., 2014).

However, social network support might not always be available (Pickard et al., 2000; Pickard et al., 2007). Female labour participation, smaller family sizes, and greater geographic dispersal of families can reduce the availability of informal caregivers (De Klerk et al., 2009; LaPlante et al., 2001; Linders, 2010; Lowenstein and Daatland, 2006). Not only a lack of availability can hinder support from the social network; utilization of support by people with chronic illness can also be hindered by a reluctance to ask and receive support from social network members. People can for instance be hesitant to ask for (more) care or support because they experience a lack of autonomy over their life when someone provides support or cares for them (Hammarström and Torres, 2010; Janlöv et al., 2005; Kwak et al., 2014; Galvin, 2004; Roe et al., 2001). Furthermore, people might refrain from seeking (more) help if an experienced lack of reciprocity in the relationship with the care provider causes them to feel unhappy or uncomfortable (Martire et al., 2002; McCann and Evans, 2002; Newsom, 1999; Newsom and Schulz, 1998; Wolff and Agree, 2004). People can also be reluctant to seek (more) help because they do not want to burden others (Cahill et al., 2010; Linders, 2010) and because they feel guilty asking for and receiving support from their social network (Cahill et al., 2010).

What this study adds

To date, many studies investigating social network support have focused on the support of close relatives such as partners and children (LaPierre and Keating, 2013; Nocon and Pearson, 2000; Rogers et al., 2014). Furthermore, studies investigating barriers to ask and receive support have also predominantly focused on support by partners and children (see for instance: Martire et al., 2002; Newsom and Schulz, 1998; Wolff and Agree, 2004). However, next to support for self-management from partners or children, people with chronic illness might also benefit from support offered by other network members, such as friends and neighbours. They can serve a critical role in helping (older) adults to stay in their own home; for instance by fulfilling practical tasks such as monitoring that someone is okay, shopping, transportation or assistance with household maintenance (Barker, 2002; Bridge, 2002; Egging et al., 2011; Lapierre et al., 2013; Litwak and Szelenyi, 1969; Nocon et al., 2002). Support by other social network members can substitute support from partners and children when this is not adequately available (Barker, 2002) or can supplement support received from partners and children.

This exploratory study aims to answer the following research questions:

1. *How do social network members outside the nuclear family support chronic illness self-management?*
2. *What barriers do people with chronic illness experience to ask and receive support from social network members?*

Methods

Design

For this exploratory study we conducted individual semi-structured interviews with 10 people with a chronic illness between July and December 2013.

Participants

All participants for the study were recruited from the National Panel of the Chronically ill and Disabled (NPCD). This is a nationwide prospective panel study in The Netherlands with 4,000 members. The NPCD was established to gather information on the consequences of chronic disease and disability from a

patient perspective. For the NPCD, participants are recruited through population surveys and from random samples of general practices that are drawn from the Dutch Database of General Practices. The NPCD is considered to be representative of the Dutch population of people with chronic diseases or long-term physical disabilities. NPCD is registered with the Dutch Data Protection Authority; all data are collected and handled in accordance with the privacy protection guidelines of this Authority.

We invited people from the NPCD that, for a previous study, had indicated that they were willing to participate in focus groups about self-management but were unable to participate. People did not participate in the focus groups because they were unable to travel to the location of the focus groups or were not available at the time the focus groups were held (for details of this study see: Heijmans et al., 2014). For the current study, we invited these people for an individual interview. Fifteen people were approached for an interview for the current study. Four of whom did not answer the phone after calls on three occasions. One person did not want to participate in an interview, resulting in ten participants.

Appointments for the interviews were made over the phone after which people received a confirmation letter specifying the date, time and purpose of the interview. In the letter it was mentioned that the interview would be about the self-management of their chronic illness (and possible physical disability) and the help, care or support that they receive. With this confirmation letter they were also send a questionnaire. Participants were free to choose the venue for the interview and all of the participants chose to have the interview at home.

Data

To visualise the contributions of specific social network members to chronic illness self-management, participants were requested to fill in a diagram they received before the interview. They were asked to write down the names of the people that they considered important for their self-management in a diagram consisting of three concentric circles (Vassilev et al., 2014). They were instructed to put the names of the people that were most important to them in the inner circle, people that were less important in the second circle, and people that were least important in the outer circle. Participants were allowed to place any type of person in the circle; friends, family, professionals, etc. During the interview the interviewers (GW and MH) discussed the role and contributions of any social

network member that was put down in the circle diagram. This name generator approach allowed us to discuss the contributions of specific social network members with the respondents, instead of having to ask questions about the contributions made by general role categories (such as family, friends, etc.). The name generator approach provided rich data on one's social network.

During the interviews participants were asked questions about their health, self-management and the contributions to self-management of people in the circle diagram. For these questions a semi-structured interview guide was designed by the interviewers (GW and MH). Respondents were asked to talk about the nature of the relationship with every person mentioned in the diagram, distance to that person, and type and frequency of contact. The interviewers asked them how that specific person was involved in the self-management of their chronic illness. Secondly; the interviewers asked them if they experienced any obstacles or problems with asking that person, and social network members in general, for help. If additional social network members were mentioned during the interview, they were included in the circle diagram. The first two interviews were conducted by both interviewers and the remaining eight interviews were conducted by GW. The interviews were tape-recorded and fully transcribed.

Analysis of interviews

Audio recordings were analysed qualitatively by a thematic analysis approach (Braun and Clarke, 2006) using MaxQDA software. We used open coding and axial coding to identify relevant phrases and themes (Boeije, 2010). The first three interviews were independently read by two researchers (GW and MH) to identify themes in the data (open coding). Discrepancies between findings of both authors were resolved through discussion and together they made an initial coding framework. GW read the other seven transcripts and identified emerging themes. After coding of the remaining 7 interviews, the authors discussed the coding framework and chose main themes by grouping together related subthemes (axial coding). Together they selected quotes to include in the article to reflect the findings.

Results

Interviews ranged in length from 38 minutes to 108 minutes, with an average length of 72 minutes. Participants ranged in age from 40 years to 89 years (mean=62 years). Five of the respondents were male and five were female. Three out of 10 participants were living alone at the time of the interview. The participants differed in the number and types of health problems they suffered from (table 3.1).

Table 3.1 Health problems of interview respondents (n=10)

| Respondent | Health problems (chronic diseases and physical disabilities) |
|------------|--|
| 1. | Cardiac arrhythmia, Epilepsy, balance disorder, hearing problems |
| 2. | Diabetes |
| 3. | Bronchitis, back problems, incontinence |
| 4. | Multiple Sclerosis (MS) |
| 5. | Asthma, Hernia, leg paralysis |
| 6. | Heart failure, balance disorder, deformed hand |
| 7. | Multiple Sclerosis (MS) |
| 8. | Diabetes, Dupuytren's contracture, leg paralysis, incontinence |
| 9. | Rheumatism (Lupus) |
| 10. | COPD |

Five themes were identified in the interviews. These themes were: the contributions of people outside the nuclear family to chronic illness self-management, the contributions of partners to self-management, the contributions of children, availability of support when this is necessary, and barriers to ask and receive support.

Content of the circle diagram

The majority of people (7 out of 10 respondents) have partners they live with and 6 out of 10 respondents also have adult children (not living with them). Partners and children are considered the most important source of support for self-management of a chronic illness or disability in everyday life.

Partners are without exception placed in the inner circle. This is not the case for children, they are also sometimes placed in the second circle. In the second circle brothers and sisters, nephews/nieces and the domestic help are most often mentioned. In the third circle colleagues, friends, and neighbours are most often

mentioned. This indicates that, from the respondents' perspective, these people are less important for the daily management of their illness or disability. Within specific role categories (such as 'friends' or 'children'), not all network members were placed in the same circle. Some friends were for instance placed in the second circle, whereas other friends were placed in the third. For examples of circle diagrams respondents filled in, see figure 3.1 and 3.2. We chose to portray a circle diagram that contained relatively few social network members, and a circle diagram that contained quite a lot of social network members. We also chose a circle diagram by a man as well as a woman.

As mentioned in the introduction of this article, most studies are focused on support for people with chronic illness by partners or children. This study specifically focuses on information about the contributions made by people outside the nuclear family, such as neighbours, friends and other family members. To place the contributions by people outside the nuclear family into perspective of the overall support system of people with chronic illness, we will also describe the contributions made by partners and children.

Figure 3.1 Example of a circle diagram

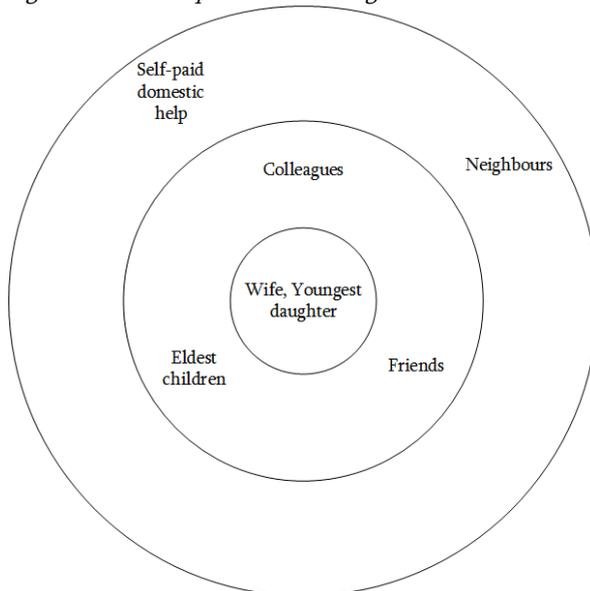
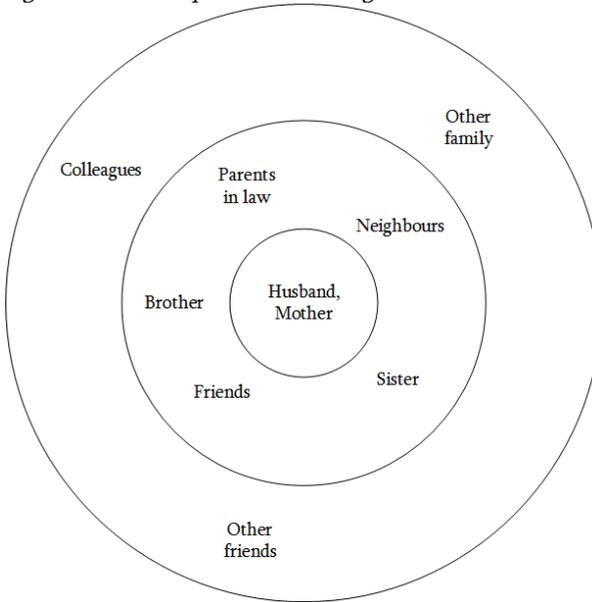


Figure 3.2 Example of a circle diagram



Contributions by people outside the nuclear family

Support for everyday life work

Neighbours, friends and other family members, such as brothers, sisters, nephews/nieces, mainly contribute to self-management by providing support for everyday life work (for the definition of various types of ‘work’ see the introduction of this article). In many cases contributions to everyday life work are not made because of an illness or physical disability. A neighbour who brings food, a neighbour who helps carry heavy boxes or comes for coffee, a friend who cooks; these are all examples of help that is not directly given because of the illness or disability that someone has. Nonetheless, it is help that can benefit self-management, because patients can spend the time and energy that they would have spent cooking or lifting boxes to tend to their health instead of busying themselves with domestic tasks.

“My brother helps me when this is necessary, he carries stuff for me. But that’s not because I have COPD. And when it comes to the household, I help him because he’s got two left hands. And I see my neighbours quite often, we exchange newspapers. I would ask them to change a lamp for me if that was necessary.” (Female, 65).

People outside the nuclear family also provide support in unforeseen or emergency situations, such as watching someone's children during an unexpected hospital visit, or doing household chores when someone is bedbound.

People outside the nuclear family do not often provide support for illness-related work. The type of support for illness-related work that is most often received from other social network members is support provided by exercising with someone, for instance going to the pool with someone to swim or taking walks.

Because people with chronic illness are often older, not many of them still have living parents. Only two respondents stated that their parents (in law) were still alive, and in only one case did they provide support.

Contributions made by neighbours

Some respondents mention that they want to maintain clear boundaries in the relationship with their neighbours. They indicate that they do not want to interact with their neighbours too frequently and that they only want to receive help occasionally. Respondents are hesitant to overstep the boundaries of neighbourliness and ask too much of their neighbours.

“Sometimes I don’t see them for a couple of weeks. I don’t want to be on their doorstep every time I feel like talking to someone. They might like me a lot, I like them a lot, but I don’t want to burden them. That’s what it is. They might think: ‘O, there she is again’. I don’t want that.” (Female, 89).

Because neighbours live close by they are able to help with routine chores in and around the house, such as carrying groceries, working in the garden, or fixing a light on the balcony. They can also provide help that is instrumental in facilitating mobility of people with chronic illness, such as helping someone in a wheelchair down the stairs in the parking garage of an apartment building. However, neighbours are less likely to help with tasks or chores that are not located in or around the house.

“My neighbour prefers to stay here in his own surroundings. So he doesn’t mind working in the garden here, and he wouldn’t mind hanging a painting on the wall, but I wouldn’t take him away from here and ask him to go somewhere with me”. (Respondent 1, male, 81).

People with chronic illness are not always on good terms with their neighbours. One of the respondents states that there is little contact between people in her neighbourhood.

“You say hello when you run into each other in the street, but that is it. It’s a shame, but that’s how it is. We live at the end of the street and our neighbours don’t like it when they have to accept packages for us when we’re not home. So if they don’t want to do that.. we won’t ask them to do groceries for us. If they can’t even accept a package.” (Female, 53).

Another respondent stated that he was close to his neighbours, but that they moved away. It is not always easy to properly get to know new residents in the neighbourhood.

Contributions of people from church and community organizations

Three respondents that go to church mention that they value the people they know there, because they see them regularly and they show an interest in their health situation. By showing an interest in one’s health situation, by listening, and by praying church members provide support for biographical work. Furthermore, church members can help people with chronic illness to find and access support if that is needed.

“If something went wrong and I would need help. I could ask a woman from church. She tells us if someone is ill or needs help, and then we can go visit them. And if I didn’t know where to find help, she would probably be able to tell me where to go. There’s also someone from church who helps me with my taxes.” (Male, 72).

Next to church, people can benefit from participating in other community organizations, such as a centre for the elderly where they organize activities. These community organizations can contribute to biographical work, by preventing loneliness and social isolation.

“There is a centre for the elderly close by. They organize a lot of activities. You meet a lot of people there. Otherwise I think it would be difficult to meet people. On Friday we always go for coffee. And we have a regular table there. And we take computer classes there sometimes. Last week I went to a

class about shopping on the internet. We participate in those a lot. And when we moved here I went to the bridge club. I also met a lot of people there.” (Female, 81).

Support for biographical work offered by friends

Respondents specifically mention that friends, next to the support for everyday life work, provide support by listening to people, asking them to share their problems and tell them about their health.

“But friends are mainly emotionally involved. That is not very practical, but is mainly the interest they show in you. My wife has a friend that used to be a nurse, and she is also strongly interested in me.” (Male, 81).

Support by colleagues

Four of the respondents have jobs. They indicate that their colleagues are not involved outside the work environment, but can provide support at work, by helping practically by carrying things, or (in the case of a superior) adjusting the demands of the job to accommodate the needs and possibilities of someone with a chronic illness or disability. Furthermore, they can take over tasks if people are unable to continue their work when their health deteriorates. Experiences at work however are not all positive. One respondent (Female, 40) states that her employer wanted to fire her when she gave birth to a stillborn child, when her pregnancy was terminated due to her disease. She does state that she is happy with her colleagues, one of whom has Crohn’s disease and understands her struggles at work and the things she encounters as a result of her disease.

Limits to the support of people outside the nuclear family

Respondents mention that if friends, neighbours or family members are in need of support themselves this can be a barrier to ask or receive support from them. Two respondents indicate that they have siblings that have the same disease as they do. If resources (e.g. time and money) are scarce and there are multiple people in a family that need support, patients might not receive as much support as they need. Many other social network members (for instance siblings or friends) suffer from the consequences of old age. This might also be a reason why social network members are unable to provide support or why they are in need of support themselves.

Interviewer: "Do you have other family that could help you? If you would have to go somewhere or do something in the house or would have to arrange something? Or if your wife would be away?"

Respondent: "Well no. That would mean that my brother would have to come here, but he's also 70 years old. To put my pants on. In 5 years he can barely put his own pants on. My sister also needs me more than I need her."
(Male, 76).

What also hinders asking or receiving support from people outside the nuclear family is that they often live far away. Large physical distance is a barrier to ask and receive care or support from the social network. Furthermore, people are busy with their own lives.

"The fact that everybody is spread all over the country makes it harder. I think that 50 years back, when everybody lived in the same village, these things [finding support in your social network] were much more attainable. The physical distance is larger between people and I think the government forgets that. It's not unwillingness, it's a lack of possibilities. Friends also have a job and they really aren't waiting to come to my house and clean here."
(Female, 53).

Independent of the current contributions of social network members, respondents say they can count on them to provide support in case of emergencies or unforeseen situations. There is a general availability of help or support when someone unexpectedly needs to go to the hospital, when someone needs groceries, when there is work in the house hold that is non-routine (such as painting the walls or repair work), or when someone becomes ill.

Interviewer: "What if you'd break your leg and you would need help for six weeks to clean or do groceries. Could you ask people you know for help?"

Respondent: "Yes, my brother would help me. Or friends. I have at least eight friends. Well I can say that now, but you never know how it will be. But I think they would help me." (Female, 65).

The contributions of partners and children to self-management

Partner as the primary caregiver

Partners are in all cases considered the primary caregiver. They take on the responsibility for the wellbeing of the other person. Partners for instance accompany their spouses to healthcare professionals, administer medication, help putting on elastic support stockings, offer help when making trips or going on holiday, help with cooking or other household work, and provide emotional support and encouragement. Their contributions are more diverse in nature than the contributions made by other social network members such as friends and neighbours. As mentioned above, friends and neighbours rarely contribute to illness related work, whereas partners contribute in many different ways.

“My partner is most important. He supports me in everything and he’s been through everything with me. You always carry things together. When I get sick he is the one who keeps everything going, and when I can’t do anything in the household he takes over. When we’re supposed to go somewhere and I can’t go, he stays with me”. (Female, 40).

Partners are also the first persons to provide support in crisis situations and unexpected circumstances. Partners for instance take their spouse to the hospital in case of an emergency or taking care of a wound that their partner has gotten due to a fall.

The evolving nature of the support offered by a partner

The support offered by partner changes and evolves when the capabilities and support needs of their spouse changes. When someone is unable to fulfil their responsibilities due to their illness, partners jump in and take on new responsibilities in the relationship. For instance, taking a paid job to earn a living instead of their spouse when their spouse was formerly responsible for the household income.

“I had another hernia, so I received benefits. But the money we received wasn’t very much. And I did have two kids and we just bought a house. Luckily I have a very resourceful wife who decided that she would go back to work again to support us”. (Male, 76).

Health problems can also strengthen people's sense of dependency on their partner, practically as well as emotionally, and can create a sense of vulnerability.

"I worry a lot because of my past and what I saw during the Indonesian National Revolution following the end of World War II. I never used to be afraid, but since I am in the wheelchair things have changed. Now I do not like to be alone anymore. My wife does not like that she needs to stay at home for me that much now, because she likes to go out and go to lectures or work with flowers at her hobby club". (Male, 81).

As exemplified by the quotes above, changes in illness conditions do not only influence illness-related work, but also influence biographical work and everyday life work. For instance: the task-division in the household, the degree of dependency on the partner, or who takes on the financial responsibility of the household.

The dynamics of the relationship with a partner can change quickly when one of the two starts functioning as a caretaker.

"I used to be really firm about it: 'You're my wife and I don't want you to become my nurse'. But very slowly, because my illness progresses slowly, it changes. Because it is very comfortable to have someone that knows exactly what you need, or not, and how. But I am going to try 100% to make sure that she stays my wife and doesn't become my nurse." (Male, 59).

The contributions of children to self-management

Children mainly contribute to biographical work

Children are considered most important to self-management next to partners. Like friends and neighbours, they also often fulfil very specific roles. Children are mainly important because of their contributions to biographical work. They listen, they provide advice, and they provide company. Some respondents state that children very rarely contribute by helping with illness related work or everyday life work. They are not generally the ones to do work in the household, to administer medication or to dress a wound.

"The children and grandchildren play an emotional role of course. But practically they aren't useful. And if we would need to be taken care of, our

children wouldn't have the room to let us live with them. So that is a problem.”(Male, 81).

“My wife said: ‘The children have to deal with your illness daily’. I thought to myself: ‘Well daily, they live in other cities, that’s not daily.’”(Male, 59).

Parents state that they can specifically count on their children to help them in case solutions are needed for unforeseen situations. Parents can for instance count on their children to take them in when their house is renovated, or to visit them after they come home from the hospital.

Differences between the contributions of children

Although all respondents state that all their children are important for self-management, there are differences between children in the contributions they make. Whereas most often children do not contribute to illness-related work or everyday life work, some children will do this. And in rare cases children have specific medical, financial or technical knowledge that they use to help their parents with illness-related work or everyday life work. A daughter who is a GP can provide medical advice and helps her parent make a treatment plan, whereas a son who is an accountant provides financial advice and helps doing taxes. Informal caregivers find caregiving tasks that align with their knowledge and capabilities.

“There is a difference between children. I have a daughter who visits me once every five weeks. Not very often. But my other daughter does groceries for me every week” (Female, 89).

Limits to the support offered by children

A reason that adult children do not often contribute a lot to the illness work and everyday life work of their chronically ill parents, according to the respondents, is that they are busy with their own lives and that they often live far away. Children often have a paid job and have children of their own that they need to spend time with. Because their children are busy, parents are hesitant to ask them for support.

“You're alone very often. From early in the morning until late at night. And then they say: ‘You've got the children’. I have three daughters and two sons.

But my three daughters all have paid jobs. They come home and they have to cook dinner. And they have kids of their own that come home. So they can't spend time with me. I'll go there occasionally, but that's it." (Female, 89).

The nature of the support-relationship between chronically ill parents and their children is also not always clear cut. Some respondents indicate that they are the ones taking care of their adult children, for instance because their child recently lost a partner or because their child has more severe health problems than they do. Furthermore, respondents express the notion that it is more natural for parents to take care of their children than for their children to take care of them.

"The youngest is physically unable to help us. And our daughter also has her problems, physically. And our eldest son lives too far away. But he sometimes does finances. We worry a lot about our children's health." (Male, 76).

Barriers to ask or receive support from the social network

Hesitant to become dependent on others

Social network members contribute to self-management in many different ways, but more or other help from social network members is not always available and respondents indicate that they experience a number of barriers to ask or receive support from their social network. In general respondents mention that they are often very dependent on help from their partner. If their partner would not be able to help them anymore, they would have a hard time figuring out how to fulfil their support needs. In some cases there would be no other solution than to get professional help.

A common feeling expressed by respondents is that they want to do everything they can to maintain their independence for as long as possible (with the help of their partner). They will avoid becoming dependent on social network members as much as they can. They are hesitant to ask for and accept help.

"My husband helps me and we try and do everything together. We would like to live independently for as long as possible. So I wouldn't want any help. I don't want to think about having to wait for someone to come shower me in the morning." (Female, 81).

The importance of reciprocity

To maintain their independence respondents are willing to invest financial

resources to obtain domestic help or supportive aids. Domestic help is considered very important because it directly helps people to live independently even if they are not able to fulfil many domestic tasks themselves. Being able to pay someone is a way of safeguarding the reciprocal nature of a support relationship.

“I have a great domiciliary help. She’s been with us for six years now and she’s everything to me. It’s very nice, she’s almost like a daughter”. (Female, 81).

People with chronic illness can find inventive ways to obtain support, whilst safeguarding the reciprocal nature of the support relationship. One respondent (Male, 81) asked someone he knew to live with him for free, in exchange for help with groceries, cooking and other household tasks. Respondents indicate that asking or receiving care or support from social network members without doing something in return makes them feel like they are burdening others.

“I would barely dare to ask people I know because I know that everybody is really busy. And that it’s a burden to help someone. I would try to resolve my problems with professional help. And if that would not be available, I would look for help in my own social network. I would rather eat less and pay someone to help me than ask my friends.” (Female, 53).

One way to prevent burdening specific social network members too much, is by dividing tasks and responsibilities among social network members.

“I do feel bad about asking others for help. I know they will help me, but I find it difficult to ask them. First my husband and me try and figure things out together. And then, we make a schedule and think of people to help us. And then we ask them. We will try to not burden one person too much, but to ask many different people. And we will try and do something for them in return as well, give them a present or a ticket to the movies.” (Female, 40).

Nature of support

Whether respondents want to receive care or support from their social network is dependent on the nature of their support needs. Support for everyday life work, for instance help with doing groceries or work in the garden, can be provided by different social network members. But, in general, providing more

personal care is not seen as a suitable task for social network members (except for a partner) and respondents indicate that they want to receive this type of care from healthcare professionals.

“I would ask my neighbour to change my lamp or do groceries for tomorrow, but to give me a shower? I wouldn’t ask him that. Personal care is something different.” (Female, 65).

Although social network members can be called on for occasional help or support, they are generally not seen as a source of long-term help. In general, the respondents preferably receive long-term care or support from healthcare professionals.

“Everybody is busy nowadays. My friends have a job and they’re really not waiting to come and clean here. If I would be ill for a couple of weeks and I would ask them, they probably would, but not if it would be something structural.” (Female, 53).

Discussion

This qualitative study has been conducted in light of the decentralisation of the responsibility for the support of citizens at home to local governments by the introduction of the Social Support Act in 2007 (Kroneman et al., 2016). In 2015 municipalities received more responsibility for the support of vulnerable citizens when the Social Support Act was extended. Before municipalities will provide support to vulnerable citizens, they will inquire whether the social network is capable of providing support and what social resources people can call on (Kroneman et al., 2016). This development signals a shift from a healthcare system with a focus on professional care and support, to a healthcare system with a focus on support provided by family, friends and neighbours (Kroneman et al., 2016). This qualitative study explored the contributions of neighbours and other social network members to self-management of people with chronic illness.

Neighbours, friends and acquaintances mainly contribute to self-management by providing support for everyday life work. Other studies also found that friends and neighbours mainly contribute to everyday life work, for instance by

providing help with transportation, shopping and home maintenance (LaPierre et al., 2013; Nocon et al., 2000). These contributions are instrumental in facilitating chronically ill people to live in their own home. The unique quality of relationships with neighbours is that they are close by and can easily help if an unforeseen situation comes up or action needs to be taken quickly. Furthermore, they are likely to assist with home maintenance, because they can easily notice when something needs to be done in someone's garden or at the home. Friends provide emotional support, for instance by listening or helping someone through a difficult time, whereas neighbours are less likely to do so.

Neighbourhood relationships simultaneously involve elements of friendly distance, supportiveness, and the preservation of boundaries around personal matters and family life, with a right to privacy (Crow et al., 2002). This differentiates neighbourhood relationships from friendships, which are sources of emotional and moral support and affection. The element of social distance in neighbourhood relationships suggests that neighbourliness has clear boundaries when it comes to providing support (Bridge, 2002; Crow et al., 2002; Eriksson and Emmelin, 2013; Lapierre et al., 2013). A study found that friends were more likely than neighbours to provide assistance with more private tasks, such as personal care or financial matters. The researchers conclude that there are some instrumental care tasks that are better suited to friends, some that are better suited to neighbours, and some where the friend/neighbour distinction does not matter (LaPierre et al., 2013).

In many cases contributions by friends and neighbours to everyday life work are not made because of an illness or physical disability. Friends or neighbours can provide help with groceries or cooking, and they can lift heavy boxes or work in the garden. This support can also be given because of old age, independent of the chronic illness or physical disabilities someone has. Nonetheless, it is help that can benefit self-management, because it reduces the amount of work that people with chronic illness need to do themselves. It leaves them more time and energy to tend to their health and life in general.

In our study respondents stated that they received support from church members. A longitudinal study of contributions to self-management found that being connected to voluntary and community groups was related to better physical health and emotional well-being (Reeves et al., 2014). Social

involvement may impact on personal capabilities to self-manage, possibly through the provision of information, skills to self-manage and social support (Chinn, 2011; Jeffries et al., 2015; Kawachi et al., 1999). It is also likely that social involvement in voluntary and community organizations, such as a church, functions as a means of keeping people engaged and active in society (Campbell and Murray, 2004; Kendall and Rogers, 2007; Vassilev et al., 2013; Reeves et al., 2014).

A number of circumstances limit support utilization (requesting as well as receiving help) from social network members. Social network members often lack time to provide support or are perceived to lack time, they often live far away, and are sometimes in need of support themselves. In another study, people who applied for social support services at the municipality in the Netherlands were asked a single question about whether their family and friends could offer them more support. A large proportion stated that their family and friends were not able to do this (De Klerk et al., 2009). This confirms that people who need support do not always think their social network has possibilities to help them.

The most important contributions to self-management are made by partners and children. Partners often facilitate independent living and contribute more than other network members, through support for illness-related work, everyday life work and biographical work. Partners take on new responsibilities in the relationship when this is necessary. They provide support in routine situations as well as in emergencies or unexpected situations. Respondents mention that they are often very dependent on help from their partner. If their partner would not be able to help them anymore, they would have a hard time figuring out how to fulfil their support needs. Children mainly contribute to biographical work. Children can also have specific knowledge they can use to contribute to illness-related work or everyday life work, for instance financial or medical knowledge. What hinders contributions of children is that they often live far away and are busy with a paid job and raising their own children.

The respondents in our study state that it is difficult for them to become dependent on others. They are hesitant to burden others with their support needs. For people with chronic illness, maintaining the reciprocal nature of relationships can be a sign of control over their life and over the management of their illness. According to Rogers et al., (2014), it may be especially confronting

to ask weak ties for help, because needing support from weak ties especially emphasises that it is not possible to manage an illness adequately without the help from others. On the other hand, the involvement of weak ties carries less of the guilt associated with the feeling of having to burden someone, which plays a larger role in the intense involvement of close ties (Rogers et al., 2014). This is partly because it is easier to reciprocate the help of weak ties, whose actions are often less intense, more fleeting, and more delimited. Our results show that respondents attach a lot of value to the contributions of a domiciliary help, because the help she offers can be financially reciprocated.

Respondents feel that there is a general availability of support if they would need it. Their social network would help them if they would ask. Another study within the general population, inquiring into the general social resources people have, also found that most people feel they can call on someone they know (not otherwise specified) when they are ill and need someone to do groceries (De Boer and De Klerk, 2013). However, respondents state that the nature of the support need is an important determinant of their willingness to ask and receive support from their social network. In general, providing more personal care is not seen as a suitable task for the social network (except for a partner).

A strength of this study is that the respondents we interviewed had a diverse range of health problems and about half of them suffered from comorbidities. Their health situations show the complexity of self-management and the need to focus on self-management as a process integrated in the realities of people daily lives. The visual diagrams we used during the interviews added value to the stories of people with chronic illness and enabled us to reconstruct the contributions of all the people in the social network. A limitation of this study is that we only conducted ten interviews with people with chronic illness. It is possible that we would have come across additional viewpoints on social network support if we would have conducted more interviews.

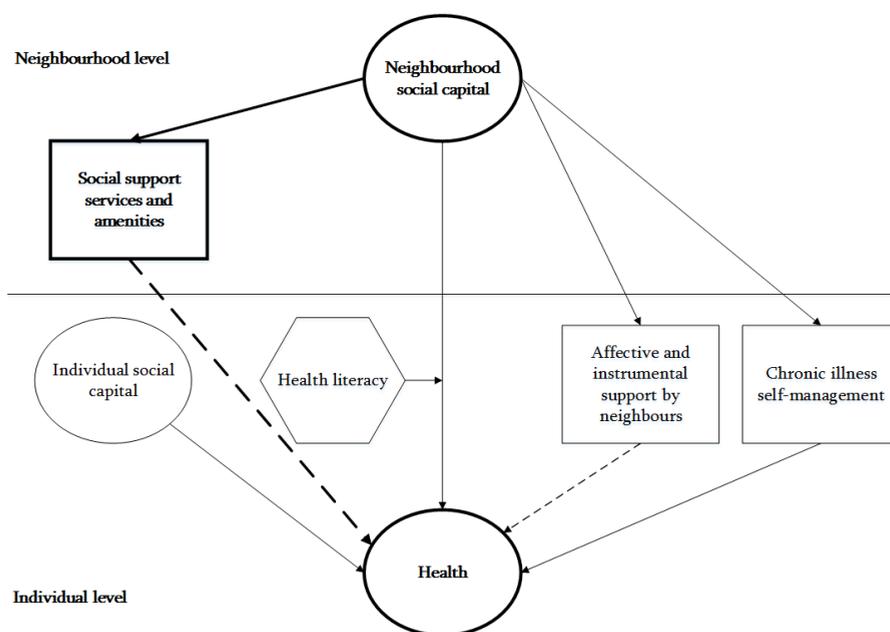
As mentioned previously, in the Netherlands municipalities are becoming increasingly responsible for the support of vulnerable groups. Before professional care and support is given, municipalities will inquire whether the social network is capable of providing support. To shed more light on the feasibility of policy goals on the substitutability of professional care and support by social network support it is necessary to complement the debate about substitution with the

voices of those this actually concerns: the patients. More research is needed to elucidate what potential there is in the social network to fulfil support needs, what can be done to facilitate social network support and in what situations professional care and support is needed.

To support people who either lack a social network they can ask for help, or people who feel that they cannot call on their network, it is also relevant to study the possibilities of strengthening health and self-management in other social environments (Campbell et al., 2004; Kendall et al., 2007; Vassilev et al., 2013). For instance, health promoting resources in neighbourhoods (such as health promoting services and amenities, affective and instrumental support by neighbours, and access to health information) might benefit those who lack adequate support to help them overcome limitations to self-management and healthy behaviour. Therefore it is relevant to study which resources are provided through neighbourhood social capital.

4

Social capital, collective efficacy and the provision of social support services and amenities by municipalities in the Netherlands



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Abstract

Background Differential provision of local services and amenities has been proposed as a mechanism behind the relationship between social capital and health. The aim of this study was to investigate whether social capital and collective efficacy are related to the provision of social support services and amenities in Dutch municipalities, against a background of decentralisation of long term care to municipalities.

Methods We used data on neighbourhood social capital, collective efficacy (the extent to which people are willing to work for the common good), and the provision of services and amenities in 2012. We included the services municipalities provide to support informal caregivers (for example: respite care), individual services and support (for example: domiciliary help), and general and collective services and amenities (for example: lending point for wheelchairs). Data for social capital were collected between May 2011 and September 2012. Social capital was measured by focusing on contacts between neighbours. A social capital measure was estimated for 414 municipalities with econometric measurements. A measure of collective efficacy was constructed based on information about the experienced responsibility for the liveability of the neighbourhood by residents in 2012, average charity collection returns in municipalities in 2012, voter turnout at the municipal elections in 2010, and the percentage of blood donors in 2012. We conducted Poisson regression and negative binomial regression to test our hypotheses.

Results We found no relationship between social capital and the provision of services and amenities in municipalities. We found an interaction effect (coefficient=3.11, 95% CI=0.72 to 5.51, $p=0.011$) of social capital and collective efficacy on the provision of support services for informal caregivers in rural municipalities.

Conclusion To gain more insight in the relationship between social capital and health, it will be important to study the relationship between social capital and differential provision of services and amenities more extensively and in different contexts.

Background

There are differences between areas in the health of their inhabitants (Diez Roux, 2001, Diez Roux and Mair, 2010, Lomas, 1998, Pickett and Pearl, 2001, Subramanian et al., 2003,). These health differences are related to social capital. Social capital develops through ties that people have with each other and is a resource that can be used by individuals and groups (Coleman, 1988). It consists of shared norms, mutual trust and shared obligations and expectations. People living in areas with more social capital experience better health (Gilbert et al., 2013; Hunter et al., 2011; Islam et al., 2006; Subramanian et al., 2003; Sundquist and Yang, 2007; Vyncke et al. 2013). One of the mechanisms behind the relationship between social capital and health might be the differential provision of public services and amenities (Kawachi et al. 1999). Social capital might benefit collective action to lobby for (increased) provision of services and amenities (Kawachi et al., 1999). However, this mechanism has rarely been studied. We aim to investigate whether social capital is related to the willingness of people to undertake collective action (collective efficacy) and whether social capital and collective efficacy are related to the differential provision of social support services and amenities.

Only a few studies have addressed the relationship between social capital and the provision of, and access to, public services and amenities. People living in countries with high social trust might have better health because they have better public services (Halpern, 2005). Furthermore, people living in communities with more social capital experience fewer problems with access to healthcare (Derose and Varda, 2009; Hendryx et al., 2002). On the individual level, studies have shown that people with more social capital utilize more health services, more regularly have health check-ups, are less likely to report barriers to care and have more trust in healthcare professionals (Burr and Lee, 2013; Chi and Carpiano, 2013; Derose et al., 2009; Drukker et al., 2004; Hendryx et al., 2001; Nguyen et al., 2005).

One study empirically tested whether there is a relationship between social capital and the activities and performance of healthcare organizations. The authors found a significant interaction effect: hospitals in communities with higher voter participation (as an indicator of social capital) and a higher percentage of board members from local community groups tended to provide

more community-oriented services (although higher community participation of residents was related to fewer community-oriented services) (Lee et al., 2004).

Putnam (2000) posits that people who are more socially connected (who have more social capital) are more likely to do good for other people and work for collective goals (see also Kawachi et al., 1999). Socially connected people more often donate blood, give money and do volunteer work (Putnam, 2000).

Being socially connected does not necessarily provide an impetus to undertake (positive) collective action (Deth and Zmerli, 2010; Halpern, 2005; Putnam, 2000). Social capital can lead to collective action for the public good if it coincides with so-called 'collective efficacy'. Collective efficacy can be described as the extent to which people are willing to work for a common goal and want to intervene on behalf of the common good (Sampson et al., 1997). Sampson et al. (1997) have found that higher levels of collective efficacy are related to lower rates of violence within neighbourhoods. Collective efficacy, however, is not only related to preventing negative events but can also be used to positively contribute to the well-being of a neighbourhood (Sampson et al. 1997). In neighbourhoods with more social capital, where there are higher levels of trust, solidarity, and shared norms, there is a higher capacity to work cooperatively to reach shared goals (Frieling et al., 2012; Kilpatrick and Abbott-Chapman, 2005; Putnam et al., 1993, Sampson et al., 1997). Improving the provision of public services and amenities that enable self-sufficiency can be one of those shared goals.

Social capital and collective efficacy

Social capital and collective efficacy are complementing concepts that have a number of similarities and dissimilarities. Both concepts tap into the constructs of trust, solidarity, and cohesion – although social capital places more emphasis on the value of social networks and the most commonly used measure of collective efficacy incorporates social control over deviant behaviour (Ansari, 2013; Coleman, 1988; Sampson et al., 1997). Cooperation requires social capital, namely, shared norms, trust, and reciprocity (Ladin et al., 2015; Sampson, 2006; Sretzer and Woolcock, 2004). Collective efficacy cannot develop and remain effective if social capital is absent (Ansari, 2013), and increased levels of social capital may foster collective efficacy and co-operative behaviour (Collins et al., 2014; Ladin et al., 2015).

Studies into collective efficacy at the neighbourhood level generally use the concept of collective efficacy of Sampson et al. (1997) that taps into social control over deviant behaviour (e.g.: Cohen et al., 2006; Collins et al., 2014; Kim and Ball-Rokeach, 2006; Maimon and Browning, 2012; Quatrin et al., 2014; Wind and Komproe, 2012). To date we have found no studies that use measures of collective efficacy that focus on the willingness to contribute to the common good of the community and improve its wellbeing instead of only preventing negative events from occurring. Although Sampson et al. (1997) emphasise the potential of collective efficacy to contribute to positive change above and beyond informal control over deviant behaviour, this aspect of collective efficacy is notably absent from the literature.

The Dutch municipal Social Support Act

The situation in the Netherlands provides a good case to study the relationship between social capital, collective efficacy and the provision of social support services and amenities for people who experience limitations to their participation in society (such as disabled people, chronically ill people or the elderly) in municipalities. The Social Support Act (Wmo), introduced in 2007 (and extended in 2015), gave municipalities responsibility for developing a coherent local social support policy (Kroneman et al., 2012; Schäfer et al., 2010). Local authorities can provide individual support as well as services and amenities that benefit multiple people. These services and amenities provided under the Social Support Act can help people maintain their autonomy by facilitating independent living and can enhance health and wellbeing within communities. Municipalities vary in the development and implementation of local support policy (Van Houten et al., 2008). This variation offers a chance to study the relationship between social capital, collective efficacy and social support policy in municipalities.

This research aims to contribute to the literature about the relationship between social capital and health by examining the relationship between social capital and the differential provision of municipal social support services and amenities. We also hypothesize an interaction effect of social capital and collective efficacy on the number of services and amenities provided by municipalities.

Hypotheses:

1. Social capital is positively related to the provision of social support services and amenities by municipalities.
2. There is a positive interaction effect of social capital and collective efficacy on the number of social support services and amenities provided by municipalities.

Methods

Data and measurements

We combined existing data from several sources at the municipal level. The municipality is the lowest level of responsibility for social support policy and the provision of services and amenities. Because this study did not include individual level data, this study does not fall within the scope of the Medical Research Involving Human Subjects Act and does not require ethical approval.

Provision of services and amenities

For the provision of services and amenities by municipalities, we used information from the survey used for the evaluation of the Social Support Act. Data were collected from January 2013 to the end of May 2013 through a questionnaire sent to every municipality. The questionnaire was completely or partially filled in by 338 out of 415 municipalities (a response rate of 83%). With regard to the provision of services and amenities in municipalities, the results of this questionnaire provided complete or partial data for 321 municipalities (77%). Response rates did not differ between more or less urban municipalities (Kromhout et al., 2014). Additional analyses showed that municipalities that did not provide data on the provision of support services for informal caregivers or on the provision of individual services and support, had on average a lower percentage of people in the highest income quartile within their municipality (24.5% versus 25.5%). There was no relationship between the percentage of people in the highest income quartile and the provision of services and amenities. Furthermore, there were no differences between municipalities with and without missing data in the level of social capital and collective efficacy. Therefore we do not expect that results would be different if we would have had data on the provision of services and amenities of all municipalities.

The provision of services and amenities by municipalities was measured in three ways (Vonk et al., 2010). The first indicator was the number of services that municipalities provide to support informal caregivers (maximum is nine; e.g. advice, education/training, counselling, respite care and financial support). The second indicator was the number of different individual services and support that the municipality offers (maximum is 27; e.g. domiciliary help, adaptation of the house and meal supply). The third indicator was the number of general and collective services and amenities that are available within municipalities (maximum is 13; e.g. a lending point for wheelchairs and mobility scooters, collective transport facilities and sports facilities for disabled people).

Social capital and collective efficacy

Data

Information about social capital and collective efficacy was obtained through WoOn, the 'Housing and Living Survey 2012', commissioned by the Ministry of the Interior and Kingdom Relations. WoOn 2012 is representative of residents of the Netherlands, 18 years and above. The data were collected among 69,336 people in all municipalities between September 2011 and May 2012 (response rate of 58%). On average there were 168 respondents per municipality, with a minimum of 1 and a maximum of 3,077 respondents (SD=310.5). Data were collected by telephone, face to face interviews and through the internet. Participants were randomly selected from the population of Dutch households with at least one person aged 18 years or above. About half of municipalities have between 20,000 and 50,000 inhabitants, about a third have less than 20,000 inhabitants, 10% have between 50,000 and 100,000 inhabitants, and about 5% have more than 100,000 inhabitants (Statistics Netherlands (CBS), 2014).

Social capital

Because social capital is inherent in and develops through social relations, social capital was measured by focusing on social contacts between neighbours. Social capital within municipalities was based on five questions on contacts among neighbours: contact with direct neighbours, contact with other neighbours, whether people in the neighbourhood know each other, whether neighbours are friendly to each other, and whether there is a friendly and sociable atmosphere in the neighbourhood.

Response categories were 'totally agree', 'agree', 'neutral', 'don't agree', and 'totally don't agree' (thus ranging from 1 to 5). Variables and the resulting scales

were coded such that higher values indicate more social capital. We applied ecometrics (Raudenbush and Earls, 1999, Raudenbush, 2003) using MLwiN 2.24, to aggregate the measurement of social capital to the municipal level. We followed the approach described by Mohnen et al. and adjusted for sex, age, education, income, employment status, home ownership, and years of residence (Mohnen et al., 2011). By aggregating individual responses to the municipal level using the ecometric method, we adjusted for differences in the number of respondents per municipality, differences between individuals within municipalities, and individual response patterns on the five questions. This resulted in a three-level model; one level for municipalities, another for individuals, and the last level for the items measuring social capital. The measure of municipal social capital is based on the municipal level residual, indicating the degree to which the social capital of a municipality differs from the grand mean. A positive score means a higher level of social capital than average. The reliability of the social capital measure depends on the variance at the three levels in the model (Hox, 2002). Its interpretation is similar to Cronbach's alpha in psychometrics scale analysis. The reliability of the social capital measure is estimated by:

$$\lambda_k = \frac{\sigma^2}{\sigma^2 + \frac{\tau^2}{J_k} + \frac{\omega^2}{nJ_k}}$$

In this formula σ^2 is the variance at the municipal level, τ^2 is the variance between individuals per municipality, and ω^2 is the variance between the items. J_k is the number of individuals in municipality k . The number of items that measure social capital is denoted by n (see also Mohnen et al., 2011). The reliability of our social capital measure on the municipal level was 0.69. A value above 0.60 is considered to be adequate (Moss et al. 1998).

Collective efficacy

To create a reliable measure of collective efficacy, we used a range of indicators that we expect to capture (a part of) the construct 'collective efficacy' (Box 1). Given our dependent variable, we used measures that focus on willingness to positively contribute to the common good.

The first indicator was based on a single question from WoOn 2012 which measures the degree to which respondents feel responsible for the liveability of their neighbourhood. This question is answered on the same 5-point scale as the

social capital measure. We coded the question in such a way that a higher score means a higher level of responsibility. We also aggregated the response to the abovementioned question to the municipal level by using the econometric approach (Raudenbush et al., 1999; Raudenbush, 2003). We used the municipal level residual of answers to this question. The other measures which we expect to capture aspects of the construct ‘collective efficacy’ are described in box 4.1.

Box 4.1 Indicators of collective efficacy

- Average return of charity collections per inhabitant of a municipality in 2012 in euros (Central Bureau on Fundraising, 2013).
- Voter turnout at the municipal elections of 2010 (Dutch Electoral Council, 2013).
- Percentage of people in a municipality that has registered as a blood donor in December 2012 (Sanquin, 2014).
- The percentage of people within a municipality that registered at ‘burgernet’ (citizenweb) in October 2013. Burgernet is an initiative from municipalities and the police. Citizens can register in their own municipality to be notified in case of a safety threat, such as theft, burglary, or a missing person case. Registered citizens are asked to look out, this can help the authorities to find a suspect or missing person (Burgernet, 2013).
- Percentage of people within a municipality that has registered as an organ donor in October 2013 (National Donor Registration, 2013).

Because collective efficacy cannot develop if social capital is weak or absent, we examined the correlations between social capital and the possible indicators of collective efficacy. Furthermore, we investigated the results of an exploratory factor analysis for further information on the possibility to construct a measure of collective efficacy based on all or some of these indicators. We chose indicators of collective efficacy based on their correlation with social capital and the results of the factor analysis.

Municipal control variables

We expected a relationship between the provision of services and amenities, the level of social capital, the level of collective efficacy and the social composition and urbanity of the municipality. Therefore we included a number of characteristics of municipalities in 2012 to take into account possible confounders in the relationship between social capital, collective efficacy and the provision of services and amenities. Urbanity was based on the number of addresses per km² (1=Urban=more than 2,500 addresses/km², 2=Semi-

urban=1,500-2,499 addresses/km², 3=Intermediate urban-rural=1,000-1,499 addresses/km², 4=Semi-rural=500-1,000 addresses/km², 5=Rural=up to 500 addresses/km²). We included the percentage of the population 65 or older and the percentage of people in the highest income quartile. The younger and wealthier a population, the less we expected them to appeal to the municipality for services and amenities to support their health and self-sufficiency, either because they are in better health or because they may more often choose to purchase individual services instead of relying on municipal provisions. Statistics Netherlands (CBS) (2014) provided information about these municipality characteristics.

Analytic strategy

We fitted three regression models to test our hypotheses. In the first model, we estimated the association of social capital, collective efficacy, the percentage of 65 and older, the percentage of people in the highest income quartile and urbanity with the support services municipalities offer for informal caregivers. The second model estimated the association of the same independent variables with the provision of individual services and support at the social support (Wmo) office. The third model estimated the association of these variables with the provision of general and collective services and amenities. All models were first estimated with only main effects and subsequently the interaction between social capital and collective efficacy was added. We used Poisson regression, appropriate for the analysis of count data, for the first and third models and negative binomial regression for the second model. A Poisson distribution requires that the variance of a dependent variable is equal to the mean, which was not the case for the second model. To deal with overdispersion, we used a negative binomial regression model (Verhoef and Boveng, 2007). Regression analyses were performed using Stata, with a significance level of 0.05.

Additionally, we estimated models including a three-way interaction between urbanity, social capital and collective efficacy to investigate whether the relationship between social capital, collective efficacy and the provision of municipal services and amenities varies by urbanity.

Variance inflation factors were examined for each variable included in the regression models. None of the regression models displayed signs of multicollinearity. Variance inflation factors in our models did not exceed 2, whereas values of 4 or 10 are often used as cut-off points indicating multicollinearity (O'Brien, 2007).

Results

Descriptive statistics

Table 4.1 shows the descriptives of the three measures of the provision of services and amenities under the Social Support Act, social capital, the possible indicators of collective efficacy, and the municipal control variables. In 2012 Dutch municipalities varied in the services and amenities they provided for their inhabitants.

Table 4.1 Descriptive statistics of social support services and amenities provided within municipalities, social capital, collective efficacy indicators and confounding variables

| Concepts | Variables | Data source | Year | Range in dataset | Mean | SD |
|---------------------------------------|---|---|------|------------------|------|------|
| Social support services and amenities | Number of support services for informal caregivers (n=300) | Netherlands Institute for Social Research | 2012 | 1-9 | 5.3 | 1.6 |
| | Number of individual services and support (n=321) | Netherlands Institute for Social Research | 2012 | 0-27 | 12.0 | 6.4 |
| | Number of general and collective services (n=304) | Netherlands Institute for Social Research | 2012 | 2-13 | 7.8 | 2.3 |
| Social capital | Social capital (n=414) | WoOn 2012 | 2012 | -0.28-0.25 | 0 | 0.09 |
| Collective efficacy | Responsibility for the liveability of the neighbourhood (n=414) | WoOn 2012 | 2012 | -0.15-0.08 | 0 | 0.03 |
| | Average charity collection returns per inhabitant (n=405) | CBF | 2012 | €0.04-12.6 | €3.5 | €1.4 |

- table 4.1 continues -

- table 4.1 continued -

| Concepts | Variables | Data source | Year | Range in dataset | Mean | SD |
|------------------------------|---|-------------------------|------|--------------------------|--------|---------|
| | Voter turnout at the municipal elections (n=405) | Dutch Electoral Council | 2010 | 40.4-80.1% | 56.5% | 0.07% |
| | Percentage of registered blood donors in a municipality (n=414) | Sanquin | 2012 | 0.08-27.0% | 8.7% | 2.7% |
| | Percentage of registered inhabitants at Burgernet in a municipality (n=399) | Burgernet | 2013 | 0.03-21.8% | 8.5% | 3.7% |
| | Percentage of registered organ donors in a municipality (n=405) | Donor register | 2013 | 6.4-28.6% | 21.1% | 3.2% |
| Municipality characteristics | Percentage of inhabitants 65 and older (n=414) | Statistics Netherlands | 2012 | 7.9-27.7% | 17.5% | 2.8% |
| | Percentage of people in the highest income quartile (n=406) | Statistics Netherlands | 2012 | 14.7-43.9% | 25.2% | 4.8% |
| | Variables | Data source | Year | Category | Number | Percent |
| | Urbanity of municipality(n=414) | Statistics Netherlands | 2012 | Urban | 14 | 3.4 |
| | | | | Semi-urban | 62 | 15.0 |
| | | | | Intermediate urban-rural | 86 | 20.8 |
| | | | | Semi-rural | 145 | 35.0 |
| | | | | Rural | 107 | 25.9 |

Table 4.2 shows the correlations between social capital and the six possible indicators of collective efficacy. The responsibility people feel for the liveability of their neighbourhood, average charity collection returns per inhabitant, voter turnout at the municipal elections, and the percentage of registered blood donors within a municipality were significantly related to social capital. Exploratory factor analysis of the six possible indicators, using the principal factors method, identified one factor (eigenvalue of 1.34) with positive factor loadings varying between 0.36 and 0.73. This factor included the responsibility people feel for the

liveability of their neighbourhood, average charity collection returns per inhabitant, voter turnout at the municipal elections, and the percentage of registered blood donors within a municipality. We found negative factor loadings for the percentage of members of Burgernet and the percentage of organ donors. The percentage of members of Burgernet and the percentage of organ donors were also not significantly related to social capital. Therefore, we used as indicators for collective efficacy the responsibility people feel for the liveability of their neighbourhood, average charity collection returns per inhabitant, voter turnout at the municipal elections and the percentage of registered blood donors within a municipality. We standardised these variables and created a scale of these four indicators of collective efficacy. The reliability of this measure, based on cronbach's alpha, is 0.65.

Table 4.3 shows that there was no significant relationship between social capital and the provision of the three types of services and amenities. There were fewer general and collective services in rural municipalities compared to urban municipalities.

There were no significant interaction effects of social capital and collective efficacy on the three types of services and amenities provided by municipalities (not in table). The estimated coefficients for the main effects of social capital and collective efficacy did not change when we included the interaction in the three models. Additional analyses showed a significant positive relationship between the interaction of social capital and collective efficacy and the provision of support services for informal caregivers in rural municipalities (coefficient=3.11, 95% CI=0.72 to 5.51, $p=0.011$). The relationship between social capital, collective efficacy, the provision of collective services and amenities and individual services and support did not vary by urbanity.

Table 4.2 Pearson correlation of social capital and collective efficacy indicators, p-values in parentheses, pairwise deletion (min n=395, max n=414)

| | 1. | 2. | 3. | 4. | 5. | 6. | 7. |
|--|----|-------------------|-------------------|-------------------|--------------------|--------------------|--------------------|
| 1. Social capital | 1 | 0.55 (p<0.001) | 0.50 (p<0.001) | 0.38 (p<0.001) | 0.11 (p=0.026) | 0.06 (p=0.245) | 0.08 (p=0.113) |
| 2. Responsibility for the liveability of the neighbourhood | | 1 | 0.32 (p<0.001) | 0.29 (p<0.001) | 0.10 (p=0.0513) | -0.04 (p=0.419) | -0.03 (p=0.548) |
| 3. Average charity collection returns per inhabitant | | | 1 | 0.60 (p<0.001) | 0.31 (p<0.001) | 0.02 (p=0.663) | -0.18 (p<0.001) |
| 4. Voter turnout at the municipal elections | | | | 1 | 0.28 (p<0.001) | 0.01 (p=0.804) | -0.15 (p=0.002) |
| 5. Percentage of registered blood donors in a municipality | | | | | 1 | -0.03 (p=0.491) | 0.10 (p=0.040) |
| 6. Percentage of registered inhabitants at burgernet in a municipality | | | | | | 1 | 0.09 (p=0.080) |
| 7. Percentage of registered organ donors in a municipality | | | | | | | 1 |

Table 4.3 Poisson (models 1 and 3) and negative binomial regression (model 2) of social capital and collective efficacy on the provision of social support services and amenities

| | Model 1 (Support for informal caregivers) (n=297) | | | Model 2 (Individual services and support) (n=318) | | | Model 3 (General and collective services) (n=301) | | |
|---------------------------------|---|---------------|---------|---|---------------|---------|---|----------------|---------|
| | Coef. | 95% CI | P-value | Coef. | 95% CI | P-value | Coef. | 95% CI | P-value |
| <i>Intercept</i> | 1.66 | 1.35 to 1.98 | <0.001 | 2.43 | 2.06 to 2.81 | <0.001 | 2.25 | 2.00 to 2.50 | <0.001 |
| <i>Independent variables</i> | | | | | | | | | |
| social capital | -0.06 | -0.86 to 0.74 | 0.882 | 0.25 | -0.70 to 1.20 | 0.611 | 0.33 | -0.32 to 0.99 | 0.319 |
| collective efficacy | -0.03 | -0.13 to 0.06 | 0.485 | -0.07 | -0.18 to 0.04 | 0.238 | 0.00 | -0.08 to 0.08 | 0.983 |
| percentage 65 and older | 0.00 | -0.02 to 0.02 | 0.838 | -0.01 | -0.03 to 0.01 | 0.433 | 0.00 | -0.01 to 0.02 | 0.813 |
| highest income quartile | 0.00 | -0.01 to 0.01 | 0.836 | -0.01 | -0.02 to 0.01 | 0.420 | 0.00 | -0.01 to 0.00 | 0.272 |
| <i>Urbanity of municipality</i> | | | | | | | | | |
| urban | Ref. ¹ | Ref. | Ref. | Ref. | Ref. | Ref. | Ref. | Ref. | Ref. |
| semi-urban | 0.03 | -0.29 to 0.34 | 0.862 | 0.09 | -0.29 to 0.46 | 0.650 | -0.10 | -0.35 to 0.15 | 0.438 |
| intermediate urban-rural | 0.06 | -0.26 to 0.39 | 0.711 | 0.07 | -0.32 to 0.45 | 0.734 | -0.14 | -0.39 to 0.12 | 0.303 |
| semi-rural | -0.02 | -0.35 to 0.32 | 0.929 | 0.03 | -0.36 to 0.43 | 0.869 | -0.21 | -0.47 to 0.06 | 0.123 |
| rural | 0.00 | -0.35 to 0.36 | 0.986 | 0.05 | -0.37 to 0.46 | 0.823 | -0.29 | -0.57 to -0.01 | 0.041 |
| <i>Pseudo R-squared</i> | 0.002 | | | 0.002 | | | 0.006 | | |

¹ Ref.=reference category

Discussion

The trend in the Netherlands towards decentralisation of social support policy provided us with an opportunity to study a possible mechanism in the relationship between social capital and health. This is – as far as we know – the second study that puts the hypothesis on social capital and service provision to the test and – just as the earlier study – without evidence in favour of this hypothesis. Overall, the models in this study had little predictive value and were unable to explain variation in the municipal provision of social support services and amenities.

We looked at social capital at a local level by examining contacts in the neighbourhood and we used several indicators of collective efficacy. The indicators that we used provided us with measures of collective efficacy that focus on the neighbourhood (the degree of responsibility people experience), a measure of the willingness people have to exert their influence for the common good at the municipal level (voter turnout at the municipal elections), and a more general indication of the degree to which people are willing to contribute to the common good (average charity collection returns and percentage of blood donors).

In additional analyses we found a relationship between the interaction of social capital and collective efficacy and the provision of support services for informal caregivers in rural municipalities. This implies that social capital may be a valuable asset for the provision of services and amenities in rural areas when levels of collective efficacy are higher. More research is needed to investigate whether and how different mechanisms behind the relationship between social capital and health vary according to urbanity.

Lee et al. (2004) studied the relationship between social capital and the provision of community-oriented health services by hospitals in the US and also did not find conclusive evidence for this relationship. They report a significant interaction between voting participation and community representation on the governance board of hospitals. They also report that in counties with greater engagement in community activities and volunteer work, hospitals provided fewer services that were aimed to promote community health (Lee et al., 2004). They propose that communities with higher participation in social activities and voluntarism may find other ways to fulfil their need for health services.

Therefore, there may be less necessity for hospital involvement in community service provision. In Dutch municipalities, there may be a higher availability of informal help and support in areas with more social capital and collective efficacy. It is possible that we did not find evidence for the relationship between social capital, collective efficacy and municipal services and amenities because we were not able to include the availability of informal help and support.

Three types of social capital can be distinguished: bonding, bridging, and linking social capital. 'Bonding' social capital refers to relationships between people in homogeneous networks with similar social identities (intragroup relations). 'Bridging' social capital refers to relations between people in heterogeneous networks (intergroup relations) (Putnam, 2002). If municipalities have residents that are more connected to their neighbours, we expect that there is a larger potential to undertake action – even if there is little bridging social capital *between* neighbourhoods within municipalities. This study however did not provide information on specific neighbourhood networks. Linking social capital consists of more vertical and formal relations between people who differ in terms of institutionalized power and resources (Sretzer and Woolcock, 2004). We did not have a measure of linking social capital, but this may be an important resource to facilitate contact between citizens and local government officials responsible for municipal support policy. It is possible that residents experience that local government officials are not approachable and that they cannot influence municipal policy.

A methodological strength of this article is the use of the econometric approach to construct a measure of social capital. Use of the econometric approach resulted in a measurement that takes into account differences between municipalities in the number of respondents as well as differences between municipalities in the characteristics of the respondents (Raudenbush et al., 1999; Raudenbush, 2003).

We did not have data on services and amenities for all municipalities in the Netherlands. We found no differences in the level of social capital and collective efficacy between municipalities with and without missing data on the provision of services and amenities. Therefore we do not expect that results would be different if we would have had data on the provision of services and amenities by all municipalities.

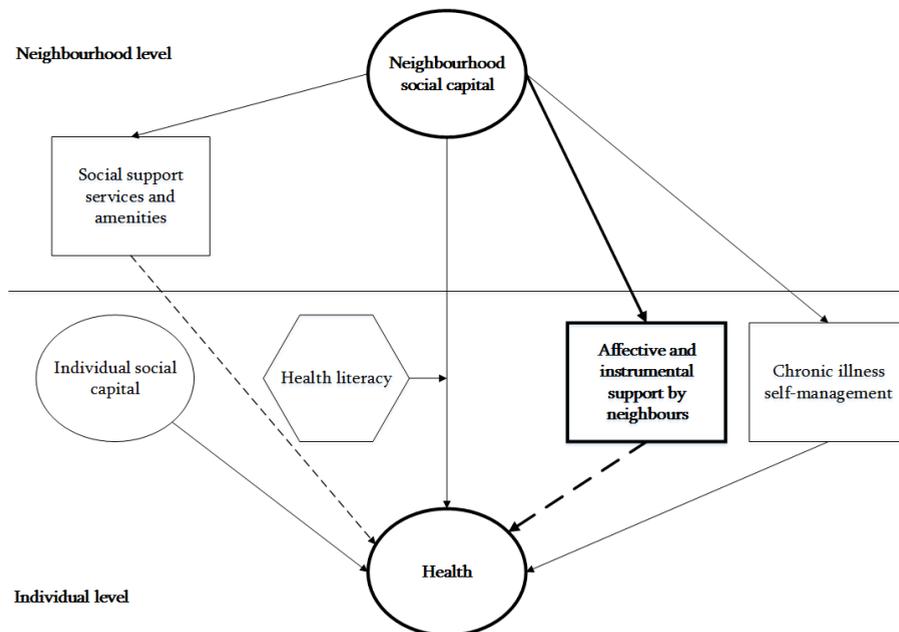
Our research has not provided evidence for the increased provision of social support services and amenities as a mechanism behind the relationship between social capital and health. Other factors that we were not able to incorporate in our study may be more important for municipal policy than the factors we studied. Because municipalities have the responsibility to formulate the content of social support policy, political differences between municipalities may cause variation in the provision of services and amenities. Future research could include political differences between municipalities. Furthermore, we could not measure the degree of collective efficacy specifically for health related goals and we did not have information on the actual effort put into lobbying for social support services and amenities by residents. A more specific measure of collective efficacy could possibly provide more insight into the relationship between social capital and the provision of services and amenities.

We also do not know whether the practical availability of different services and amenities was equal between municipalities in 2012. For instance, regarding support services for informal caregivers, some municipalities may have had a wider array of possibilities for respite care than other municipalities. Future research can possibly include more specific types of services and amenities. Finally, in other studies it is relevant to not only include the provision of services and amenities by municipalities but also to incorporate experienced access to services and amenities by residents. Residents may be more likely to undertake action to improve access to services and amenities that already exist, instead of lobbying for new services and amenities.

Our findings call for a more elaborate study of the relationship between social capital, collective efficacy and the provision of social support services and amenities in other contexts. Not only the Dutch situation, but also other countries with decentralised healthcare systems provide a situation that is suitable to test this hypothesis (e.g. Finland). Furthermore, it is possible that this mechanism can be better tested in the next few years when policy changes have been implemented for a longer time and citizens have had more experience with municipal support policy.

5

Neighbourly support of people with chronic illness: is it related to neighbourhood social capital?



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Abstract

Background The neighbourhood may provide resources for health. It is to date unknown whether people who live in neighbourhoods with more social capital have more access to practical and emotional support by neighbours, or whether this is a resource only available to those who are personally connected to people in their neighbourhood. We investigated whether support by neighbours of people with chronic illness was related to neighbourhood social capital and to individual neighbourhood connections. Furthermore, we investigated whether support received by neighbours differed according to demographic and disease characteristics of people with chronic illness.

Methods We collected data on support by neighbours and individual connections to neighbours among 2,272 people with chronic illness in 2015. Data on neighbourhood social capital were collected among 69,336 people in 3,425 neighbourhoods between May 2011 and September 2012. Neighbourhood social capital was estimated with econometric measurements. We conducted multilevel regression analyses. People with chronic illness were more likely to receive practical and emotional support from neighbours if they had more individual connections to people in their neighbourhood.

Results People with chronic illness were not more likely to receive practical and emotional support from neighbours if they lived in a neighbourhood with more social capital. People with chronic illness with moderate physical disabilities or with comorbidity, and people with chronic illness who lived together with their partner or children, were more likely to receive support from neighbours.

Conclusion To gain more insight into the benefits of neighbourhood social capital, it is necessary to differentiate between the resources only accessible through individual connections to people in the neighbourhood and resources provided through social capital on the neighbourhood level.

Background

Residential neighbourhoods are meaningful contexts of life and are important for health and wellbeing of their inhabitants (Cramm and Nieboer, 2015; Diez Roux, 2001; Diez Roux and Mair, 2010; Greenfield and Reyes, 2014; Lomas, 1998; Pickett and Pearl, 2001; Subramanian et al., 2003). The neighbourhood has gained increasing attention as a site for social support and help, for instance for elderly in the context of 'ageing in place' (Gardner, 2011; Gray, 2009; Van Dijk et al., 2013; Wiles et al., 2011). Theories on the significance of neighbourhood relationships have traditionally emphasized their instrumental value (Cantor, 1979; Litwak and Szelenyi, 1969). Research shows that neighbours usually fulfil tasks that require proximity (for instance monitoring that someone is okay), tasks that are practical (for instance shopping, transportation or assistance with household maintenance) and non-intimate (not concerning personal care or nursing tasks for instance (Barker, 2002; Bridge, 2002; LaPierre and Keating, 2013; Litwak et al., 1969; Nocon and Pearson, 2000)). This study aims to gain more insight into support by neighbours, specifically for people with chronic illness. Previous studies have focused on support by neighbours for elderly in the general population (Barker, 2002; Gardner, 2011; Nocon et al., 2000), but to date there is no information on support by neighbours specifically for people with chronic illness.

To manage the demand put on healthcare systems due to long-term health problems, there has been an increasing focus on the responsibility of patients and their social network for health (Lipszyc et al., 2012; Maarse and Jeurissen, 2016). However, people with long-term health problems, such as people with chronic illness, might not always be able to rely on support from social network members, such as friends and family. The growing number of people with chronic illness and the changing age structure of the population, place high demands on available informal caregivers and raise questions regarding the future availability of informal care (De Boer and De Klerk, 2013; Pickard et al., 2000; Pickard et al., 2007). Social network members, who possibly have to balance other responsibilities, including work and child care, can be busy and therefore limited in the amount of help they can provide (LaPlante et al., 2004). Furthermore, social network members might live far away and physical distance can be a barrier to support (De Klerk et al., 2009; Linders, 2010; Wellman and Wortley, 1990). When there are barriers to support from social network

members, or when people with chronic illness otherwise lack the resources they need for health, the neighbourhood can possibly provide compensatory resources. A previous study found that people with less frequent contact with friends and family were more likely to report good health when they lived in neighbourhoods with more social capital (Mohnen et al., 2015). This study however did not provide information on the specific compensatory resources provided in neighbourhoods with more social capital. It is valuable to shed more light on the specific resources that are provided in neighbourhoods, such as practical and emotional support.

A rich literature on neighbourhood resources has shown that social capital in the neighbourhood on both the individual and the neighbourhood level can benefit people's health. Here we link the literature on support for people with chronic illness and the literature on neighbourhood resources by asking the question whether more support by neighbours is available for chronically ill people in neighbourhoods with more social capital. Or is more support by neighbours only available if people with chronic illness are personally more connected to their neighbours, i.e. when they have more individual social capital?

Social capital is defined by the resources that develop through social relations. These resources can facilitate the achievement of goals and contribute to health and wellbeing (Coleman, 1988). Social capital can be conceptualized on a number of analytic levels, among which the macro level (countries, states and regions) (see for instance: Kawachi et al., 1997), the meso level (neighbourhood and blocks) (see for instance Lochner et al., 2003), and the individual micro-level (individual social relationships, trust and norms) (Portes, 1998; Veenstra, 2000). Social capital on the individual level differs from social capital at the community level, for instance the neighbourhood. Individual social capital is a personal asset and consists of resources that are only accessible to individuals that are part of the relationships that generate specific resources (Portes, 1998). On the other hand, social capital on a community level is the source of collective resources that do not belong to a specific individual, or inhere in a specific set of relationships, but are part of the social structure of a community (Coleman, 1988). Social capital on the community level provides public resources that can benefit even people with poor personal social connections. Neighbourhoods with more social capital might for instance be more successful at realizing informal social control, which might result in reduced violence (Sampson et al., 1997).

More neighbourhood safety benefits all neighbourhood residents and not only those personally connected to specific others in their neighbourhood. In addition to a distinction made between social capital on different levels, it is also possible to distinguish between bonding and bridging social capital. The distinction between 'bonding' and 'bridging' social capital helps to differentiate between people in homogeneous networks with similar social identities (intragroup relations) and relations between people in heterogeneous networks (intergroup relations) (Putnam, 2002).

There is evidence that community or collective social capital in the neighbourhood can benefit health of people in the general population as well as people with chronic illness (Gilbert et al., 2013; Hunter et al., 2011; Islam et al., 2006; Subramanian et al., 2003; Sundquist and Yang, 2007; Vyncke et al., 2013; Waverijn et al., 2014). Examples of public resources provided through neighbourhood social capital that can benefit health, are increased informal social control and increased access to health information (Kawachi et al., 1999; Kawachi and Berkman, 2000; Sampson et al., 1997). Another possible mechanism might be the provision of support by neighbours (Kawachi et al., 1999, Kawachi et al., 2000). In a neighbourhood with more collective social capital there might be more of a general tendency to help each other (for instance with work in the garden, carrying groceries, or by having a conversation on the street), even when people don't know each other very well. Others, however, stress the importance of being connected to people or networks that generate specific resources, and state that access to social support is restricted to people who are embedded in specific relationships with those that can provide social support (Carpiano, 2006; Carpiano, 2008). Simply living in a neighbourhood with more social capital, without having relationships with specific neighbours or being integrated into neighbourhood networks, might not be enough for an individual to gain access to social support by neighbours.

Not only might support by neighbours depend on personal integration in the neighbourhood and individual connections to others. The use of social support by neighbours might also differ according to demographic and disease characteristics of people with chronic illness. Based on demographic and disease characteristics, people with chronic illness might either have more access to support by neighbours or might have a higher need for support by neighbours. Regarding differential access to neighbourhood resources, a study showed

differences in the effect of neighbourhood social capital based on duration and intensity of exposure to the neighbourhood environment (Mohnen et al., 2013).

To gain more insight into the relationships between support by neighbours, neighbourhood social capital and individual neighbourhood connections, we will explore differences in the use of support by neighbours according to demographic and disease characteristics of people with chronic illness and we will test the following hypothesis:

Hypothesis:

People with chronic illness more often receive support from neighbours if they live in neighbourhoods with more social capital, beyond individual connections to neighbours.

Methods

Data

National Panel of the Chronically ill and Disabled (NPCD)

We used data from the 'National Panel of the Chronically ill and Disabled'. This is a nationwide prospective panel study in The Netherlands, established to gather information on the consequences of chronic disease and disability from a patient perspective. For the NPCD, participants are recruited from random samples of general practices that are drawn from the Dutch Database of General Practices. They are selected according to the following criteria: diagnosis of a somatic chronic disease by a certified medical practitioner, aged >15 years, not permanently institutionalized, aware of the diagnosis, not terminally ill (life expectancy >6 months according to their general practitioner), mentally capable of participating, and sufficient mastery of Dutch. Members of NPCD are also recruited on the basis of a self-reported moderate or severe physical disability from several national population surveys conducted by the Netherlands Institute for Social Research, the Dutch Ministry of Infrastructure and the Environment and Statistics Netherlands. In 2015, the NPCD consisted of more than 4,000 people with chronic illness or physical disability. Annually, 500 new panel members are selected via the standardized procedure to replace panel members who withdrew or who had participated for the maximum term of four years. The NPCD is registered with the Dutch Data Protection Authority; all data are

collected and handled in accordance with the privacy protection guidelines of this Authority. Panel members fill in questionnaires at home twice a year. For this study in 2015 a questionnaire was sent to 2,893 people with chronic illness and filled in questionnaire were received from 2,272 people (response rate of 79%). Respondents were on average older than non-respondents (65 years versus 60 years) and more often had multiple chronic diseases (56% versus 48%). In our sample, there were in total 832 neighbourhoods, with on average three respondents per neighbourhood (the minimum number of respondents per neighbourhood is one, the maximum number of respondents per neighbourhood is seventy).

Measurements

Support from social network members and people in the neighbourhood

People with chronic illness were asked whether they received support in the previous year from their family or other people they know, and what type of support. They were asked whether they received help with domestic work (cooking, doing groceries, doing the laundry, cleaning, etc.); help with personal care (taking a shower, getting dressed, putting on support stockings, getting up and going to bed, eating, etc.); nursing tasks (wound dressing, injections, help with taking medications, etc.); help arranging practical matters or guidance undertaking activities; help with their medical treatment; help making lifestyle changes (for instance regarding to diet or exercise); emotional support, understanding and listening; help with requesting professional care, domestic aids, care or services or with doing administrative tasks; help with transportation to family, medical professionals, the hospital or making trips; practical support with chores in and around the house; help with understanding and applying information about health, illness or medication; help with formulating goals or making choices with regard to medical treatment or life in general.

If people with chronic illness received support, they were asked whom they received this support from, including partners, children (residential and non-residential), other family, people from the neighbourhood (excluding family living in the neighbourhood), friends and acquaintances, volunteers, other people with chronic illness or physical disability, someone from church or other faith community. People with chronic illness were said to have received support from neighbours if they had received one of the above mentioned forms of support from people in the neighbourhood. We did not define 'the

neighbourhood', so people with chronic illness answered these questions based on their own perception of what constitutes their neighbourhood. In this study we constructed a measure of whether or not people receive support from neighbours based on the five types of support people with chronic illness most often received from people in the neighbourhood.

Individual neighbourhood connections

We constructed a measure of individual neighbourhood connections based on three questions. We included the questions:

1. About how many adults do you recognize or know by sight in your neighbourhood – would you say no adults, a few, many, or most? (“No adults”, “a few adults”, “many adults”, “most adults”)
2. In the past 30 days, how many of your neighbours have you talked with for 10 minutes or more? (“None”, “one or two”, “three to five”, “six or more”)
3. How many of your friends live in your neighbourhood? (“None”, “a few”, “many”, “most or all”)

Again, we did not define ‘the neighbourhood’, so on the individual level this variable reflects residents’ individual perceptions of what constitutes their neighbourhood and who their neighbours are. For the analyses we standardized the variables and created a scale. A higher score indicates being more connected to people in the neighbourhood ($\alpha=0.61$, mean=0.00, std. dev.=0.76, min=-1.93, max=1.88).

Neighbourhood social capital

Neighbourhood social capital was based on five questions of about social contacts among neighbours: contact with direct neighbours; contact with other neighbours; whether people in the neighbourhood know each other; whether neighbours are friendly to each other; and whether there is a friendly and sociable atmosphere in the neighbourhood. Response categories were ‘totally agree’, ‘agree’, ‘neutral’, ‘don’t agree’, and ‘totally don’t agree’ (thus ranging from 1 to 5). Variables and the resulting scales were coded so that higher values indicate more social capital. We applied ecometric analysis, using a three-level hierarchical model (Raudenbush et al., 1991; Raudenbush and Sampson, 1999; Raudenbush, 2003), to aggregate the measurement of social capital to the neighbourhood level (Waverijn et al., 2014). The reliability of the social capital measure on the neighbourhood level was 0.74.

Information about neighbourhood social capital was acquired through WoOn, the 'Housing and Living Survey 2012', commissioned by the Ministry of the Interior and Kingdom Relations. WoOn 2012 is representative of residents of the Netherlands of 18 years and above. The data were collected among 69,336 people between September 2011 and May 2012 (response rate of 58%) in 3,425 neighbourhoods with an average of 20 respondents per neighbourhood. In our study neighbourhoods were spatially defined based on 4-digit postal codes. Postal codes in the Netherlands are used to identify small geographical areas that comprise between 1–8 km². On average there are 4,000 residents in a postal code area (Statistics Netherlands (CBS), 2015). The size of neighbourhoods is generally larger in rural areas than in urban areas. Statistics Netherlands gave us access to data of neighbourhoods that had a minimum of three respondents; which resulted in a dataset containing 2,544 neighbourhoods with an average of 27 respondents per neighbourhood. Data were collected by telephone, face to face interviews and internet. Participants were randomly selected from the population of Dutch households with at least one person aged 18 years or above. We used the postal code of the residential address of people with chronic illness to add the information on neighbourhood social capital to the dataset containing information on support utilization and health of people with chronic illness.

Demographic characteristics

On the individual level we included a number of demographic characteristics, namely: gender, coded as a dummy variable; age in 2015; educational level, coded as either low (no education until the lowest high school degree), intermediate (vocational training and the highest two high school degrees), high (university of applied sciences degree and university degree); living status (living alone or living together with a partner or children).

Disease characteristics

We also included a number of disease characteristics of people with chronic illness, namely: the nature of the first diagnosed chronic disease (including cardiovascular diseases, cancer, respiratory diseases, diabetes, musculoskeletal diseases, neurological diseases and digestive diseases) as reported by the general practitioner; duration of the first diagnosed chronic disease; and number of chronic diseases (one or multiple chronic diseases). The presence of physical disabilities was measured by a self-reported validated Dutch questionnaire that consists of 24 items about activities in daily life and the ability to see/hear (De

Klerk et al., 2006). The level of physical disability was defined by the level of motor disability. People with mild motor disabilities were those who had problems with one or multiple daily activities, such as household tasks. People with a moderate motor disability not only experienced problems with household tasks, but were also limited in other areas and had problems with mobility. People with a severe motor disability have at least one activity they are unable to perform without support.

Professional homecare

To not only take into account informal support received, but also take into account professional support, we included a variable indicating whether people with chronic illness received professional homecare. Professional homecare could be help with domestic work (cooking, doing groceries, doing the laundry, cleaning, etc.); help with personal care (taking a shower, getting dressed, putting on support stockings, getting up and going to bed, eating, etc.); nursing tasks (wound dressing, injections, help with taking medications, etc.); and support aimed at promoting self-reliance and the ability people have to live independently.

Neighbourhood characteristics

Urbanity

An indicator of the urbanity of the municipality in which a given neighbourhood is located, was provided by Statistics Netherlands (CBS) (2015) , and was based on the number of addresses per km² (1=Urban=More than 2,500 addresses/km², 2=Semi-urban=1,500-2,499 addresses/km², 3=intermediate urban-rural=1,000–1,499 addresses/km², 4=Semi-rural=500/599 addresses per km², 5=Rural=Up to 500 addresses per km²).

Socioeconomic status of the neighbourhood

To measure the socioeconomic status of the neighbourhood we used data on the average annual taxable income per household in neighbourhoods in 2012, based on information of all residents of a neighbourhood provided by Statistics Netherlands (2015). Average annual taxable income was divided into 4 categories; less than 22,100 euro per year, between 22,101 and 30,000 euro per year, between 30,001 and 35,739 euro per year, and more than 35,739 euro per year. In the analyses we included the percentage of households per neighbourhood with a taxable income less than 22,100 euro per year.

Analysis

Descriptive statistics were applied to describe the characteristics of our sample. Using Stata's module to run MLwiN 2.24 through Stata, we conducted multilevel regression analyses with respondents nested in neighbourhoods, to test our hypothesis. As previously mentioned, in the analyses we used the types of support people with chronic illness most often received from people in the neighbourhood. We investigated whether there was a relationship between support by neighbours, neighbourhood social capital and individual connections in the neighbourhood. First we examined the relationship between support by neighbours and neighbourhood social capital, without taking into account individual connections in the neighbourhood and differences in demographic and disease characteristics between people with chronic illness (Model 1). Second, we examined the relationship between support by neighbours and individual neighbourhood connections, without taking into account neighbourhood social capital and differences in demographic and disease characteristics between people with chronic illness (Model 2). Third, we ran a complete model including neighbourhood social capital, individual connections in the neighbourhood and demographic and disease characteristics of people with chronic illness (Model 3).

To enhance interpretability of the results, we centred the continuous variables in our models. Continuous variables were tested for linearity. No signs of non-linearity were found.

Not all people with chronic illness that responded to the questionnaire were included in the regression analyses. First, 262 people were excluded because they did not provide information about informal and professional support received. For 102 people we did not have information about neighbourhood social capital or individual connections in the neighbourhood. Of the remaining respondents, 182 people were excluded because they had missing data on demographic and disease characteristics. Univariate and multivariate regression analyses showed no significant differences between respondents who were excluded from the analyses and respondents who were included, with regard to support received, neighbourhood social capital, individual connections in the neighbourhood, and demographic and disease characteristics. The only exception was that people with a lower educational level were more likely to have missing data on support received from neighbours. However, educational level was not related to the

likelihood of receiving support from neighbours, the level of social capital of the neighbourhood one lived in, and individual connections in the neighbourhood. Therefore we do not expect that results would be different if we would have been able to include these respondents.

Results

Sample characteristics

Table 5.1 displays sample characteristics. A little more than half of the people in our sample was female and mean age was 65 years. About a third of the respondents had a low educational level and a quarter of the respondents lived alone. More than half of the respondents had multiple chronic diseases and average illness duration was 14 years. More than one third of the respondents experienced moderate or severe disabilities.

Table 5.1 Demographic and disease characteristics of people with chronic illness (n=2.272)

| | Percent |
|-------------------------------------|-------------|
| <i>Gender:</i> | |
| male | 45.6 |
| female | 54.4 |
| <hr/> | |
| <i>Age in years</i> | Mean (sd) |
| | 65.2 (13.3) |
| <hr/> | |
| <i>Education:</i> | |
| low | 32.4 |
| intermediate | 43.2 |
| high | 21.7 |
| unknown | 2.7 |
| <i>Household status:</i> | |
| living alone | 27.1 |
| living with partner and/or children | 71.7 |
| unknown | 1.1 |

- table 5.1 continues -

- table 5.1 continued -

| | | Percent |
|---|--------------|-------------|
| <i>First diagnosed chronic disease:</i> | | |
| cardiovascular disease | | 19.1 |
| respiratory disease | | 29.3 |
| musculoskeletal disease | | 12.3 |
| cancer | | 4.3 |
| diabetes | | 11.7 |
| neurological disease | | 6.4 |
| digestive disease | | 3.9 |
| other disease | | 13.0 |
| <i>Number of chronic diseases:</i> | | |
| one | | 43.6 |
| two or more | | 56.4 |
| <i>Presence and severity of physical disability:</i> | | |
| no disability | | 27.5 |
| mild disability | | 25.9 |
| moderate disability | | 29.3 |
| severe disability | | 12.2 |
| unknown | | 5.2 |
| | Range | Mean (sd) |
| Illness duration in years (n=2.230) | 0.28-83 | 13.8 (10.3) |
| | | Percent |
| Support received from people in the neighbourhood (n=2.082) | | 14.3 |
| | Range | Mean (sd) |
| Individual connections in the neighbourhood (based on standardized variables) (n=2.210) | -1.93 - 0.88 | 0.0 (0.8) |
| Self-rated general health (n=2.163) | 0-100 | 50.1 (20.8) |

Support received by neighbours

Almost half (41%) of the people with chronic illness received informal support from one or more social network members.

Fourteen percent of the people with chronic illness in our sample received one or multiple forms of informal support from neighbours, namely: emotional support and understanding (received by 7%); help with domestic work (received by 6%); practical help with chores in and around the house (received by 6%); help with transportation to family, physicians, the hospital or making trips (received by 4%); help arranging practical matters or guidance undertaking activities (received by 2%).

The percentage of people with chronic illness who received other types of support from neighbours, such as nursing care, informational support, or help with medical treatment, was less than 1% for each type of support. In the analyses we included the abovementioned five types of support most often received from people in the neighbourhood by people with chronic illness.

Neighbourhood characteristics

Table 5.2 shows that average social capital of the neighbourhoods in our sample was lower than the average level of social capital of Dutch neighbourhoods in the WoOn-dataset (a score of zero means exactly average).

Table 5.2 Descriptive statistics of neighbourhood level variables

| | Range | Mean (sd) |
|---|--------------|--------------|
| <i>Neighbourhood social capital</i> (n=771) | -0.43 – 0.26 | -0.02 (0.10) |
| | | Percent |
| <i>Urbanity</i> (n=832) | | |
| urban | | 18.6 |
| semi-urban | | 29.8 |
| intermediate urban-rural | | 23.9 |
| semi-rural | | 19.3 |
| rural | | 8.4 |
| | Range | Mean (sd) |
| <i>Neighbourhood socio-economic status</i> (n=824) | | |
| Percentage of households per neighbourhood with a taxable income less than 22,100 euro per year | 6-70 | 26.2 |

Relationship between support received from neighbours, individual connections in the neighbourhood and neighbourhood social capital

In an empty model, excluding any independent variables, there was no significant neighbourhood variation in support received by neighbours (var=0.13, std. error=0.10) (not in table). In Model 1 we included neighbourhood social capital, urbanity and socioeconomic status of the neighbourhood (not in table). There was no significant effect of neighbourhood social capital on the likelihood of receiving support from neighbours (OR=1.09, 95% CI=0.92/1.29). In Model 2, including individual neighbourhood connections, urbanity and socioeconomic status of the neighbourhood, there was a significant positive effect of individual neighbourhood connections on the likelihood of receiving support from neighbours (OR=1.47, 95% CI=1.20/1.80) (not in table).

In Model 3 we included neighbourhood social capital, individual connections in the neighbourhood, urbanity of the neighbourhood, socio-economic status of the neighbourhood and demographic and disease characteristics of people with chronic illness. People with chronic illness were more likely to receive support from neighbours if they were personally more connected to people in the neighbourhood (table 5.3). The odds of receiving support from neighbours were higher for people with chronic illness with two or more diseases compared to people with chronic illness with only one disease. Furthermore, the odds of receiving support from neighbours were higher for people with chronic illness with moderate physical disabilities compared to people with chronic illness without physical disabilities. People with severe physical disabilities also more often received support from neighbours than people without physical disabilities, but this difference did not reach the threshold of significance. People with chronic illness were less likely to receive support from people in the neighbourhood if they lived together with a partner or children. This effect was significant, beyond actually receiving support from other social network members, such as a partner or children.

Table 5.3 Logistic multilevel regression analysis of the relationship between support received from neighbours, individual connections in the neighbourhood and neighbourhood social capital (Ni=1726, Nj=668)#

| | Support from neighbours Odds ratios (95% CI) | |
|---------------------------|---|----------------|
| <i>Age</i> | 1.00 | (0.99/1.01) |
| <i>Gender:</i> | | |
| male | Ref. | |
| female | 0.89 | (0.62/1.29) |
| <i>Educational level:</i> | | |
| low | Ref. | |
| intermediate | 1.29 | (0.86/1.94) |
| high | 1.49 | (0.92/2.43) |
| <i>Household status:</i> | | |
| living alone | Ref. | |
| living together | 0.32 | (0.22/0.48)*** |

- table 5.3 continues -

- table 5.3 continued -

| | Support from neighbours Odds ratios (95% CI) | |
|--|---|------------------|
| <i>First diagnosed chronic disease:</i> | | |
| cardiovascular disease | Ref. | |
| respiratory disease | 0.92 | (0.53/1.58) |
| musculoskeletal disease | 0.89 | (0.48/1.63) |
| cancer | 1.05 | (0.45/2.46) |
| diabetes | 1.06 | (0.55/2.07) |
| neurological disease | 0.62 | (0.28/1.38) |
| digestive disease | 0.82 | (0.30/2.24) |
| other disease | 1.05 | (0.58/1.92) |
| <i>Number of chronic diseases:</i> | | |
| one | Ref. | |
| two or more | 1.53 | (1.05/2.23)* |
| <i>Illness duration</i> | 0.95 | (0.80/1.12) |
| <i>Receives support from other network members, such as partner and children</i> | 36.07 | (20.52/63.41)*** |
| <i>Receives professional homecare</i> | 1.26 | (0.81/1.95) |
| <i>Presence and severity of physical disability:</i> | | |
| no disability | Ref. | |
| mild disability | 0.85 | (0.47/1.56) |
| moderate disability | 1.83 | (1.03/3.26)* |
| severe disability | 1.38 | (0.69//2.74) |
| <i>Neighbourhood social capital</i> | 1.04 | (0.85/1.26) |
| <i>Individual neighbourhood connections</i> | 1.75 | (1.38/2.23)*** |
| <i>Urbanity:</i> | | |
| urban | Ref. | |
| semi-urban | 1.29 | (0.72/2.31) |
| intermediate urban-rural | 1.61 | (0.86/3.02) |
| semi-rural | 0.96 | (0.49/1.87) |
| rural | 0.98 | (0.42/2.26) |
| <i>Neighbourhood socioeconomic status</i> | 0.99 | (0.96/1.01) |
| <i>Var (neighbourhood) (std. error)</i> | 0 | (0) |

* p≤0.05; ** p≤0.01; *** p≤0.001

Ni=number of individuals, Nj=number of neighbourhoods

Discussion

In this study we did not find a relationship between neighbourhood social capital and support received from neighbours by people with chronic illness, beyond individual social connections to people in the neighbourhood. As far as we know this is the first study to investigate the relationship between support received by neighbours, neighbourhood social capital and individual social connections in the neighbourhood. Previous studies have focused on the benefits of neighbourhood support for other groups, for instance for elderly in the context of aging in place (Gardner, 2011; Gray, 2009; Wiles et al., 2011). Although the average age of people with chronic illness in our sample is 65, and there is thus overlap between 'elderly' in general and our sample of people with chronic illness, we specifically focused on the presence of a chronic illness.

Our results indicate that neighbours are not more likely to provide support for people with chronic illness in neighbourhoods with more neighbourhood social capital, if people with chronic illness are not personally connected to others in their neighbourhood. This suggests that it is important that people with chronic illness who would benefit from support by neighbours, are connected to people or networks in their neighbourhood that are willing and able to provide social support (as suggested by Carpiano, 2006; Carpiano, 2008). It is relevant to discover which resources are available also for those who have poor social connections to others in their neighbourhood.

Our results show that people with chronic illness with multiple chronic diseases and moderate physical disabilities are more likely to receive support from neighbours than people with chronic illness with only one chronic disease and people with chronic illness without physical disabilities. This confirms that people with chronic illness with a more complex health situation, due to comorbidity and more physical limitations, are more likely to need and therefore use support by neighbours.

We conducted our study in the Netherlands. The Netherlands is a small but densely populated country. The ageing of the population, and corresponding rise of healthcare costs, provide complex health challenges. To contain costs, the provision of social support and home care for people with physical disabilities was reformed in 2007 by the introduction of the Social Support Act (Wmo).

With the Social Support Act a greater part of the responsibility for the provision of social support was delegated to the municipal level (Kroneman et al., 2016). In 2015 long-term care was reformed and the Social Support Act was extended. This means that municipalities have become more responsible for the wellbeing of vulnerable groups and the fulfilment of their support needs. With this reform there is an increasing emphasis on care at home instead of in institutions. Municipalities have a certain degree of freedom to determine their spending on care and support (Kroneman et al., 2016). This has created opportunity for regional variation in the provision of care and support for vulnerable citizens. Coinciding with the decentralisation of social support and the focus on care at home for those with support needs, there is an increasing focus on individual responsibility for health and self-sufficiency.

Before professional care and support is given, municipalities will inquire whether the social network is capable of providing informal care and what social resources people can call on (Kroneman et al., 2016). The shift towards more individual responsibility and self-sufficiency requires a cultural change from a more government-centred healthcare system to a more family and neighbourhood-centred healthcare system (Kroneman et al., 2016). The decentralised nature of the Dutch healthcare system provides a unique cultural and socio-economic context for our study. There are other countries with a decentralised healthcare system, such as the Nordic countries in Europe. The Dutch context differs from the situation in these countries because in the Netherlands policy changes have only been implemented recently and Dutch society is still in a transition period. The reform in 2015 was implemented in a great hurry and caused social unrest because the organization of care changed drastically (Kroneman et al., 2016). Concerns that were voiced before the transition included, among others, the lack of coordination in care provision between municipalities and health insurance companies. Furthermore, there were concerns that providing informal care would become an obligation and the policy changes would create a difficult position for informal caregivers (Kroneman et al., 2016). The policy changes as well as resulting cultural changes and social unrest might play an important role in shaping the provision of support by neighbours for people with chronic illness with support needs. To gain more insight into the contribution of the cultural and socio-economic context of the Netherlands to the results found in our study, it would be beneficial to replicate this study in other countries with a decentralised

healthcare system. Another country-specific aspect that might influence results of this study is the size of neighbourhoods. In this study we used the smallest possible unit of aggregation available to us to measure social capital (based on 4-digit postal codes). The size of neighbourhoods in the Netherlands is generally larger in rural areas than in urban areas. Similar studies in other countries might therefore yield different results if the size and layout of neighbourhoods differs from neighbourhoods in the Netherlands.

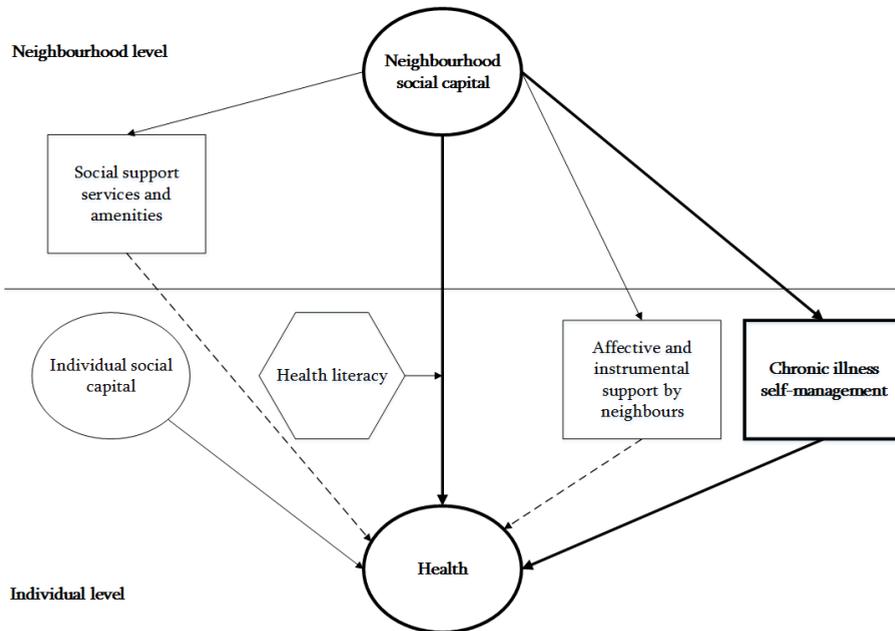
Previous studies in the Netherlands, that use the same neighbourhood definition, present evidence that neighbourhood social capital is related to individual health (Mohnen et al., 2011; Waverijn et al., 2014). However, the effects found in previous studies are small. It is possible that the effect of neighbourhood social capital in these studies is underestimated because of the crude neighbourhood measure used. Hipp and Block (2007) also state that whereas most studies have found that the size of neighbourhood effects is relatively small, this may be due to misspecification of the proper level of aggregation for these effects. Duncan et al. (2014) suggest the use of egocentric neighbourhoods. Studies have found that self-defined neighbourhoods were different from, and often smaller than, often used neighbourhood boundaries such as a predefined radius around the house and census tract boundaries (Colabianchi et al., 2014; Coulton, 2012). However, using egocentric neighbourhoods and thus not defining the boundaries of neighbourhoods, we would not be able to study the effect of neighbourhood-level variables.

There is not one single “appropriate” level to study neighbourhood effects. Rather it is possible that the effects of contextual characteristics can work at different geographical levels, also dependent on the outcome of interest. Some effects might be very localized whereas other effects might be present on a larger scale. The assumption with regard to social capital is that with geographic availability, residents run in to each other. Contacts between neighbours can then produce resources and develop a sense of community among neighbours (Völker et al., 2007). We do not know on what scale neighbours are likely to run into each other and build relationships. In our study we did not ask people with chronic illness what the distance was between them and the neighbours they had contact with. Knowledge about physical distance in neighbourhood relations may provide more insight into what the relevant spatial scale is to study resources provided by neighbourhood social capital.

To be able to draw conclusions about the benefits of neighbourhood social capital, it is necessary to gain insight in the resources provided through neighbourhood social capital and the resources that are only accessible through individual connections to neighbours. Furthermore, it is important to gain more insight into how health of people with chronic illness can be supported even when individuals themselves lack a social network and are poorly connected to people in their neighbourhood.

6

Chronic illness self-management: a mechanism behind the relationship between neighbourhood social capital and health?



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Abstract

Background Neighbourhood social capital might provide resources that can benefit chronic illness self-management. Improved self-management is a possible mechanism behind the relationship between neighbourhood social capital and health of people with chronic illness.

Methods To test this mechanism, we collected data on self-management and self-rated health among a sample of 2,091 people with chronic illness in 2013. Data on neighbourhood social capital were collected among 69,336 people in 3,425 neighbourhoods between May 2011 and September 2012. A social capital measure was estimated with econometric measurements. We conducted mediation analyses to examine whether the relationship between neighbourhood social capital and self-rated health was mediated through chronic illness self-management.

Results We found that neighbourhood social capital is related to chronic illness self-management only for people with chronic illness and mild physical disabilities and that, for this group, self-management mediates the relationship between neighbourhood social capital and health.

Conclusion Improved self-management is a mechanism behind the relationship between neighbourhood social capital and health for people with chronic illness and mild physical disabilities. It is possible that the self-management support needs of people with chronic illness with moderate or severe physical disabilities cannot be met by the resources provided in neighbourhoods, but more tailored support is necessary. More research is needed to discover mechanisms behind the relationship between neighbourhood social capital and health and elucidate which resources in neighbourhoods can benefit specific groups of people with chronic illness.

Background

There are differences in health between neighbourhoods (Diez Roux and Mair, 2010; Lomas, 1998; Pickett and Pearl, 2001; Subramanian et al., 2003). Among others, these health differences are related to social capital. Social capital is defined by the resources that develop through social relations. Individual social capital consists of resources that inhere in relationships between specific individuals. In contrast, neighbourhood social capital is defined by the resources that are available to those who belong to the neighbourhood community (Coleman, 1988), independent of the relationships they have with specific others. The resources provided through neighbourhood social capital can benefit health, for instance by promoting the diffusion of health information. Furthermore, neighbourhood social capital might stimulate social control over unhealthy behaviour (Kawachi et al., 1999; Kawachi and Berkman, 2000). Additionally, psychosocial processes (feelings of safety, being respected) may positively influence health in neighbourhoods with more social capital (Kawachi et al., 1999; Kawachi et al., 2000). Not only does social capital benefit health of people in the general population (Gilbert et al., 2013; Islam et al., 2006; Murayama, Fujiwara, and Kawachi, 2012; Sundquist and Yang, 2007; Vyncke et al., 2013), neighbourhood social capital is also related to changes in health of people with chronic illness (Waverijn et al., 2014). It is possible that neighbourhood resources benefit health of people with chronic illness because they contribute to chronic illness self-management.

Self-management of a chronic illness involves the medical management of the condition(s), such as dealing with symptoms and complex medication regimes. It also involves broader challenges, such as coping with the emotional impact of a chronic illness, making lifestyle adjustments, and integrating a chronic illness into existing roles and responsibilities people fulfil in their daily life (Barlow et al., 2002; Glasgow et al., 2003). Although healthcare professionals can support people with chronic illness in their self-management (Bodenheimer et al., 2002; Glasgow et al., 2003; Wagner et al., 2001), the largest part of chronic illness self-management takes place outside the healthcare setting. Therefore, self-management predominantly is a task of patients and their social network (Lipszyc et al., 2012; Ministry of Health, Welfare and Sports, 2013). Next to support for self-management from close ties, such as friends and family, people with chronic illness might also benefit from resources generated through weaker ties in other

environments, such as the neighbourhood (Rogers et al., 2014). It is unlikely that resources generated in the neighbourhood are illness specific, and provide information that is relevant specifically for medical management or complex medication regimes. However, these resources might benefit the way people handle lifestyle adjustments, and succeed to integrate a chronic illness into existing roles and responsibilities they fulfil in their daily life. As previously mentioned, one of the resources generated in neighbourhoods with more social capital, can be increased access to relevant information (Cattell, 2001; Chinn, 2011; Gilbert et al., 2013; Granovetter, 1973; Jeffries et al., 2015; Kawachi et al., 2000). Access to information in neighbourhoods can possibly benefit self-management of people with chronic illness through, for instance, practical information about the services and support the municipality offers, information on available social support groups, or advice about lifestyle changes. Furthermore, informal social control in neighbourhoods can promote the adoption of healthy behaviours (Aarts et al., 2010; Fisher et al., 2004). Also, increased emotional wellbeing in neighbourhoods with more social capital through feelings of safety, respect, and psychosocial support (Gilbert et al., 2013; Kawachi et al., 2000) may help people with chronic illness to gain confidence and overcome barriers to self-management. We will investigate whether neighbourhood social capital is related to self-management of people with chronic illness, and whether self-management is a mechanism behind the relationship between neighbourhood social capital and health. If chronic illness self-management is a mechanism behind the relationship between neighbourhood social capital and health, stimulating the development of neighbourhood networks (for instance by providing neighbourhood meeting points and organizing social gatherings) might be a fruitful way to support self-management of people with chronic illness.

We will test the following hypotheses:

Hypotheses:

1. There is a positive relationship between neighbourhood social capital and chronic illness self-management.
2. Chronic illness self-management is a mechanism behind the relationship between neighbourhood social capital and health.

Methods

Data

Participants

We analysed data from the ‘National Panel of people with Chronic illness or Disability’ (NPCD). This is a nationwide representative prospective panel study in The Netherlands, established to gather information on the consequences of chronic disease and disability from a patient perspective. The NPCD is registered with the Dutch Authority on Personal Data; all data are collected and handled in accordance with the privacy protection guidelines of this Authority (for more information on the NPCD, see: Waverijn et al., 2014). We used data from a questionnaire sent to people with chronic illness in 2013. The questionnaire in 2013 was sent to a sample of ,2545 people with chronic illness, of which 2,091 (82.2%) returned the questionnaire. Non-response analyses showed that people with chronic illness who filled in a questionnaire were on average older than non-responders (63 vs. 57 years old), and more often had multiple chronic diseases (49% vs. 42%).

Measurements

General self-rated health

Self-rated health was assessed with the scale ‘perceived general health’ from the RAND-36 short-form health status survey (Van der Zee and Sanderman, 1993). Respondents are asked to answer the following question: “In general how would you say your health is?” with answers on a 5-point scale, ranging from ‘excellent’ to ‘poor’. Respondents then select answers that best describe how much they agree with four statements about their health on a 5-point scale ranging from ‘totally agree’ to ‘totally disagree’. The statements are: “I seem to get sick a little easier than other people”, “I am as healthy as anybody I know”, “I expect my health to get worse” and “My health is excellent”. The scale score of perceived general health is the sum of these five items, rescaled to range from 0 (worst health) to 100 (best health) (Van der Zee et al., 1993). In our study, Cronbach’s alpha of the scale was 0.81, indicating a high internal consistency.

Self-management

The questionnaire in 2013 included a Dutch version of the twelve item self-rated Partners in Health scale (PIH-Dutch). The Partners in Health Scale has been shown to be a valid and consistent measure of patient self-management ability

(Battersby et al., 2003). The items cover a number of areas, such as to what extent patients manage the consequences of a chronic disease, actively participate in decision making in their treatment, have knowledge of their condition and treatment, and feel able to manage symptoms. As the content of the Dutch version differs from the original version, we used a different factor structure (Heijmans et al., 2015). As previously mentioned, we expect that the resources provided in neighbourhoods are relevant for the ability people have to cope with the general consequences of a chronic disease in their daily life, and not as relevant for their interaction with medical professionals or for their ability to perform disease specific management tasks (such as adhering to complex medication regimes or monitoring blood sugar levels). Therefore we only use the scale 'coping with the consequences of a chronic disease' as a self-management measure in this study. Scores on this scale range from zero to eight with higher scores indicating better self-management. The items belonging to this scale measure whether people can deal with the effect of their condition on their physical activities (such as walking, domestic chores), on their feelings (emotions and mental wellbeing), on their social contacts and relationships, and whether they succeed in maintaining a healthy lifestyle (not smoking, moderate alcohol use, healthy diet, regular exercise, dealing with stress). We calculated an average score across the four items belonging to this scale, if people had filled in at least three of the items (Cronbach's $\alpha=0.84$).

Demographic characteristics

We included a number of demographic characteristics, namely: sex; age in 2013; educational level, coded as either low (no education until the lowest high school degree), intermediate (vocational training and the highest two high school degrees), high (university of applied sciences degree and university degree); living status (living alone or living together with a partner or children); and net equivalent income. Net equivalent income was defined as the sum of the monthly net incomes of all household members corrected for household composition (Siermann et al., 2004). If information on household composition was not available we used uncorrected net income in the analyses.

Disease characteristics

We also included a number of disease characteristics, namely: the nature of the first diagnosed chronic disease as reported by the general practitioner, duration of the first diagnosed chronic disease, the number of chronic diseases (ranging

from '1' to '3 or more'), and the presence of physical disabilities (no disabilities, mild, moderate, or severe physical disabilities) as measured by a self-reported validated Dutch questionnaire that deals with activities in daily life and the ability to see/hear (for more information see: De Klerk et al., 2003).

Neighbourhood social capital

Information about neighbourhood social capital was acquired through the 'Housing and Living Survey 2012' (WoOn), commissioned by the Ministry of the Interior and Kingdom Relations. WoOn 2012 is representative of residents of the Netherlands of 18 years and above. The data were collected among 69,336 people between September 2011 and May 2012 (response rate of 58%) in 3,425 neighbourhoods with an average of 20 respondents per neighbourhood. In our study neighbourhoods were spatially defined based on 4-digit postal codes. Postal codes in the Netherlands are used to identify relatively small geographical areas that comprise between 1–8 km² and have on average 4,000 residents (Statistics Netherlands (CBS), 2016). In urban regions, these areas correspond with urban neighbourhoods; in rural regions, they can encompass small villages. Statistics Netherlands gave us access to data of neighbourhoods that had a minimum of three respondents; resulting in a dataset containing 2,544 neighbourhoods with an average of 27 respondents per neighbourhood. We used the postal code of the residential address of people with chronic illness to add the information on neighbourhood social capital to the dataset containing information on self-management.

Social capital was based on five questions about contact with direct neighbours, contact with other neighbours, whether people in the neighbourhood know each other, whether neighbours are friendly to each other; and whether there is a friendly and sociable atmosphere in the neighbourhood. We applied econometric analysis, using a three-level hierarchical model (Raudenbush and Sampson, 1999), to aggregate the measurement of social capital to the neighbourhood level. We adjusted for sex, age, education, income, employment status, home ownership and years of residence (Mohnen et al., 2011) (for more information see: Waverijn et al., 2014). The econometric method adjusts for differences in the number of respondents per neighbourhood. Also, the model parameterizes the measurement error variation and takes into account item difficulty. The econometric model partitions variance into three components: variation among neighbourhoods, variation among individuals, and variation within individuals

among items used for the social capital measure. The reliability of the social capital measure on the neighbourhood level was 0.74.

Urbanity of the neighbourhood

On the neighbourhood level we included the urbanity of the municipality in which a given neighbourhood is located. Urbanity was provided by Statistics Netherlands (CBS), and was based on the number of addresses per km² (1=Urban=More than 2,500 addresses/km², 2=Semi-urban=1,500–2,499 addresses/km², 3=Intermediate urban-rural=1,000–1,499 addresses/km², 4=Semi-rural=500/999 addresses per km², 5=Rural=Up to 500 addresses per km²).

Socioeconomic status of the neighbourhood

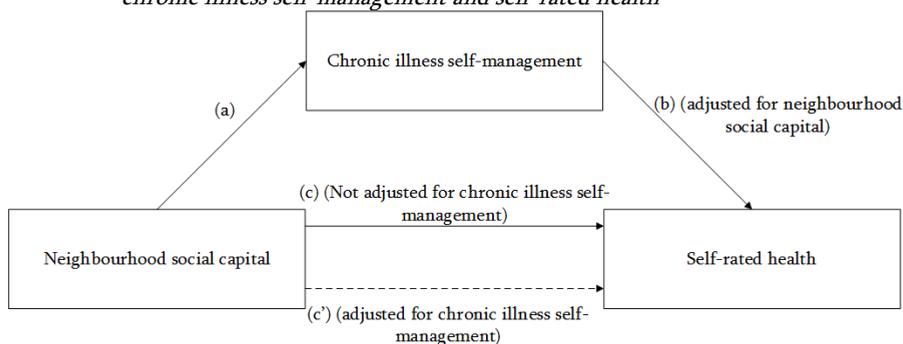
As an indicator of the socioeconomic status of the neighbourhood we used a measure of average annual taxable income per household in the neighbourhoods, based on information provided by Statistics Netherlands (CBS). Average annual taxable income was divided into four categories; less than 22,100 euro per year, between 22,101 and 30,000 euro per year, between 30,001 and 35,739 euro per year, and more than 35,739 euro per year. In the analyses we included the percentage of households per neighbourhood with a taxable income less than 22,100 euro per year.

Analysis

Descriptive statistics were applied to describe our sample. Using Stata version 14, we conducted multilevel regression analyses with respondents nested in neighbourhoods. First; we examined whether there was a relationship between chronic illness self-management and neighbourhood social capital. Second, we examined whether the relationship between neighbourhood social capital and self-rated health was mediated through chronic illness self-management (Figure 6.1). To run multilevel mediation analyses we used Stata's 'Generalized structural equation model estimation command' (gsem). The indirect effect was examined through the postestimation command 'nlcom' provided by Stata. Nlcom computes indirect effect coefficients and their standard errors. Regression analyses included the urbanity of a neighbourhood, and demographic and disease characteristics. To enhance interpretability of the results, we centred the continuous confounders. Continuous variables were tested for linearity. No signs

of non-linearity were found. Whereas linear regression assumes that model residuals are both normal and identically distributed, in our regression models residuals were not normally distributed. Therefore we ran the models using robust (White-Huber) standard errors, to take into account the violation of this assumption (Freedman, 2006).

Figure 6.1 Conceptual model of the associations between neighbourhood social capital, chronic illness self-management and self-rated health



Not all people with chronic illness that responded to the questionnaire were included in the analyses. First, 163 people were excluded because they did not provide information on self-management. Additionally, for 81 people we did not have information on neighbourhood social capital. 311 people were excluded because they had missing data on demographic and illness characteristics.

Univariate and multivariate regression analyses showed no significant differences between respondents who were excluded from the analyses and respondents who were included, with regard to self-management, social capital and demographic and illness characteristics. Therefore we do not expect that results would be different if we would include these respondents.

Results

Sample characteristics

Table 6.1 displays sample characteristics. Average self-management score of the respondents with regard to coping with the physical, emotional and social consequences of a disease, was 6.2 on a scale of 0-8. Average perceived general health in our sample was 49 points on a scale of 1-100. This is lower than average

perceived general health of the Dutch population (73 points on a scale of 1-100) (Van der Zee et al., 1993). Table 6.2 displays neighbourhood characteristics.

Table 6.1 Demographic and disease characteristics of people with chronic illness, average score on the Partners in Health-scale, 2013

| | | Percent |
|--|------------|--------------|
| <i>Sex</i> (n=2091): | | |
| male | | 43 |
| female | | 57 |
| <hr/> | | |
| | Range | Mean (sd) |
| <i>Age</i> (n=2091) | 16-93 | 64 (14) |
| <hr/> | | |
| <i>Education</i> (n=2091): | | |
| low | | 33 |
| intermediate | | 42 |
| high | | 22 |
| unknown | | 3 |
| <i>Household status</i> (n=2091): | | |
| living alone | | 27 |
| living with partner and/or children | | 72 |
| unknown | | 1 |
| <hr/> | | |
| | Range | Mean (sd) |
| <i>Net equivalent income per month</i> (n=1899): | €262-€3750 | €1553 (€627) |
| <hr/> | | |
| <i>First diagnosed chronic disease</i> (n=2091): | | |
| cardiovascular disease | | 19 |
| respiratory disease | | 18 |
| musculoskeletal disease | | 17 |
| cancer | | 6 |
| diabetes | | 13 |
| neurological disease | | 8 |
| digestive disease | | 4 |
| other disease | | 16 |
| <i>Number of chronic diseases</i> (n=2091): | | |
| one | | 42 |
| two | | 29 |
| three or more | | 29 |

- table 6.1 continues -

- table 6.1 continued -

| | | Percent |
|--|-------|-------------|
| <i>Severity of disability</i> (n=2091): | | |
| no disability | | 27 |
| mild disability | | 23 |
| moderate disability | | 30 |
| severe disability | | 14 |
| unknown | | 5 |
| | Range | Mean (sd) |
| <i>Illness duration in years</i> (n=2047): | 0-68 | 13 (11) |
| <i>Self-management</i> (n=1928): | 0-8 | 6.2 (1.5) |
| <i>Self-rated health</i> (n=1991): | 0-100 | 49.4 (21.0) |

Table 6.2 Descriptive statistics of neighbourhood level variables

| | Range | Mean (sd) |
|---|--------------|--------------|
| Neighbourhood social capital (n=763) | -0.38 – 0.26 | -0.02 (0.10) |
| | | Percent |
| <i>Urbanity</i> (n=821): | | |
| urban | | 18 |
| semi-urban | | 26 |
| intermediate urban-rural | | 24 |
| semi-rural | | 21 |
| rural | | 11 |
| | Range | Mean (sd) |
| <i>Neighbourhood socio-economic status</i> (n=824): | | |
| Percentage of households per neighbourhood with a taxable income less than 22,100 euro per year | 6-70 | 26.2 |

The relationship between neighbourhood social capital and chronic illness self-management

Neighbourhood social capital was positively related to self-management in a model without confounding variables (Model 1, table 6.3) (Path a in figure 6.1). There was no relationship between neighbourhood social capital and self-management of people with chronic illness, when taking into account demographic and illness characteristics and neighbourhood characteristics (Model 2, table 6.3). Age and illness duration were positively related to chronic

illness self-management, and the presence of mild, moderate or severe physical disabilities was negatively related to chronic illness self-management.

Table 6.3 Multilevel linear regression analysis of neighbourhood social capital and chronic illness self-management (Ni=1530, Nj=658)#

| | Chronic illness self-management | |
|--|---------------------------------|--------------------|
| | Model 1 | Model 2 |
| | Coef. (std.err) | Coef. (std.err) |
| <i>Intercept</i> | 6.15 (0.04)*** | 6.33 (0.21)*** |
| <i>Neighbourhood social capital</i> | 0.11 (0.04)** | 0.02 (0.04) |
| <i>Age</i> | | 0.01 (0.00)*** |
| <i>Sex:</i> | | |
| male | | Ref. |
| female | | 0.07 (0.08) |
| <i>Educational level:</i> | | |
| low | | Ref. |
| intermediate | | 0.09 (0.09) |
| high | | 0.07 (0.10) |
| <i>Household status:</i> | | |
| living alone | | Ref. |
| living together | | 0.08 (0.09) |
| <i>Net equivalent income</i> | | 0.0001 (0.0000)*** |
| <i>First diagnosed chronic disease:</i> | | |
| cardiovascular disease | | Ref. |
| respiratory disease | | -0.04 (0.13) |
| musculoskeletal disease | | -0.06 (0.13) |
| cancer | | 0.16 (0.17) |
| diabetes | | -0.05 (0.12) |
| neurological disease | | -0.03 (0.16) |
| digestive disease | | -0.06 (0.21) |
| other disease | | -0.14 (0.12) |
| <i>Number of chronic diseases:</i> | | |
| one | | Ref. |
| two | | -0.13 (0.08) |
| three or more | | -0.16 (0.09) |
| <i>Presence and severity of physical disability:</i> | | |
| no disability | | Ref. |
| mild disability | | -0.59 (0.09)*** |
| moderate disability | | -1.20 (0.10)*** |
| severe disability | | -1.30 (0.14)*** |

- table 6.3 continues -

- table 6.3 continued -

| | Chronic illness self-management | |
|--|---------------------------------|-----------------|
| | Model 1 | Model 2 |
| | Coef. (std.err) | Coef. (std.err) |
| <i>Illness duration</i> | | 0.01 (0.00)* |
| <i>Urbanity:</i> | | |
| urban | | Ref. |
| semi-urban | | -0.06 (0.11) |
| intermediate urban-rural | | 0.03 (0.13) |
| semi-rural | | 0.04 (0.12) |
| rural | | 0.06 (0.13) |
| <i>Neighbourhood socio-economic status</i> | | 0.00 (0.00) |
| <i>Var (neighbourhood)</i> | 0.05(0.04) | 0.00 (0.00) |

* $p \leq 0.05$; ** $p \leq 0.0$; *** $p \leq 0.001$

Ni=number of individuals, Nj=number of neighbourhoods

As there was a strong effect of the presence of physical disabilities on chronic illness self-management, we ran additional analyses to investigate whether the effect of neighbourhood social capital on self-management differed according to the presence of physical disabilities. There was a positive relationship between neighbourhood social capital and self-management for people with mild disabilities (coef.=0.13, std. err=0.06, $p=0.027$), but not for people without physical disabilities (coef.=0.06, std. err=0.06, $p=0.349$), moderate (coef.=-0.05, std.error=0.07, $p=0.509$) or severe (coef.=-0.07, std.error=0.09, $p=0.459$) physical disabilities. Based on these results we examined whether self-management mediates the relationship between neighbourhood social capital and health only for people with chronic illness and mild physical disabilities.

Mediation of the relationship between neighbourhood social capital and self-rated health through chronic illness self-management

For people with chronic illness and mild physical disabilities, there was a positive relationship between self-management and self-rated health (path b in figure 6.1, coefficient=5.46, std. error=0.39, $p=0.000$).

In a model without chronic illness self-management, there was a positive association between neighbourhood social capital and self-rated health of people with chronic illness and mild physical disabilities (path c in figure 6.1, coefficient=2.37, std.error=0.98, $p=0.016$). In a model including chronic illness self-management, there was no longer a significant association between

neighbourhood social capital and self-rated health of people with chronic illness and mild physical disabilities (patch c' in figure 6.1, coefficient=1.55, std. error=0.98, p=0.113).

The results of the 'nlcom' command provided in Stata indicated that chronic illness self-management was a mediator between neighbourhood social capital and self-rated health of people with chronic illness and mild physical disabilities. The indirect effect of neighbourhood social capital on self-rated health through chronic illness self-management was significant (coefficient=0.66, std.error=0.30, p=0.027). This means of the total positive effect of neighbourhood social capital on self-rated health (coefficient=2.21, std. error=1.05, p=0.035), 29.7% was mediated through chronic illness self-management.

Discussion

We investigated whether neighbourhood social capital was related to chronic illness self-management and whether the relationship between neighbourhood social capital and self-rated health was mediated through chronic illness self-management. We found that neighbourhood social capital was positively related to self-management of people with chronic illness and mild physical disabilities. We found that a third of the total effect of neighbourhood social capital on self-rated health for people with mild physical disabilities was mediated through chronic illness self-management.

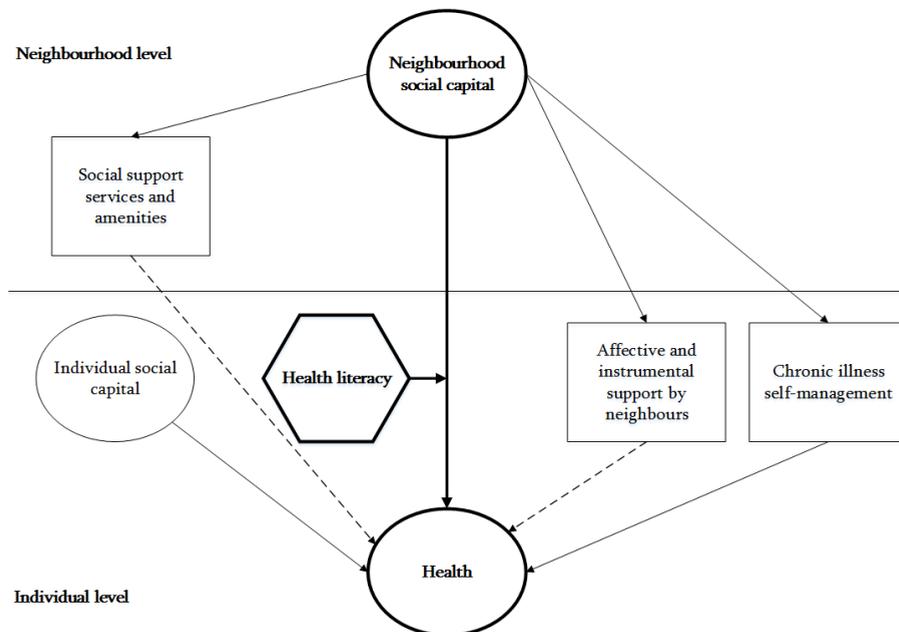
Previous studies have found significant associations between self-management of people with diabetes and the individual perceptions of neighbourhood characteristics, such as neighbourhood problems (including, among others, crime, trash, access to exercise facilities), neighbourhood safety, neighbourhood aesthetics and experienced social cohesion and support in the neighbourhood (Gary et al., 2008; Smalls et al., 2015). As far as we know this is the first study to focus on the relationship between neighbourhood social capital and chronic illness self-management. We found that neighbourhood social capital was only related to self-management of people with chronic illness and mild physical disabilities. It is possible that neighbourhood resources do not benefit self-management of people without physical disabilities as they experience few self-management challenges and are not in need of neighbourhood resources to improve self-management. The presence of moderate or severe physical

disabilities on the other hand severely hinders coping with the consequences of a chronic disease (Heijmans et al., 2015). It is possible that neighbourhood social capital does not provide resources for people with chronic illness and moderate or severe physical disabilities. It is for instance possible that people with chronic illness and mild disabilities benefit from increased access to information or social norms about exercise and an active lifestyle, whereas people with moderate or severe physical disabilities are unable to benefit from information about exercise programs. Our findings are based on an explorative analysis that should be independently tested on a different dataset.

The lack of a relationship between neighbourhood social capital and self-management, may (partly) be due to our operationalization of the neighbourhood. There are many approaches to delineating the neighbourhood. Most quantitative studies of neighbourhoods rely on census data or political boundaries to operationalize the neighbourhood (for a discussion on the operationalization of the neighbourhood, see for instance: Bader and Ailshire, 2014; Coulton, 2012; Weaver, 2015). It is possible that we would have been able to discover a relationship between neighbourhood social capital and chronic illness self-management if we would have used a smaller level of aggregation to define the neighbourhood. It is unlikely that individuals have strong ties with the majority of the other people in a neighbourhood measured on the scale of the neighbourhoods in our study (based on 4-digit postal codes). However, resources provided by neighbourhood social capital that can benefit health and self-management, such as the transmission of information as well as informal social control, can be provided through weak ties and do not require dense social networks (Granovetter, 1973).

A strength of this study is that we have a measure of neighbourhood social capital not based on data collected among the chronically ill in our sample, but among a representative sample in the general population. A weakness of this study is that we do not have information about the individual connections of people with chronic illness to the people in their neighbourhood. However, previous research has shown that neighbourhood social capital is related to changes in self-rated general health of people with chronic illness, when taking individual social capital into account (Waverijn et al., 2014). To gain more insight into the possible benefits of neighbourhood social capital for people with chronic illness, it is relevant to systematically investigate the presence of specific types of resources in neighbourhoods.

Associations between neighbourhood social capital, health literacy and self-rated health among people with chronic illness



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Abstract

Background Health literacy skills are important for health and self-management of people with chronic illness. Neighbourhood social capital can provide resources, such as access to information and informal social control over unhealthy behaviour. The benefit of these resources, and the access people have to these resources, might depend on levels of health literacy.

Methods We investigated whether neighbourhood social capital is differentially related to health of people with chronic illness according to health literacy skills. This study focused on health literacy skills in four domains, related to the ability to access and understand health information and to the ability to perform self-management.

Results We found a significant positive interaction between social capital and health literacy skills in two domains related to the ability to access and understand health information.

Conclusion Our results suggests that health literacy enhances the ability people have to gain access to and use neighbourhood resources to benefit health. There is no interaction effect between social capital and health literacy skills in the other two health literacy domains. More research is needed to investigate how people with chronic illness can benefit from knowledge, support and other social resources for health and self-management, also if they have limited health literacy skills.

Background

The burden put on healthcare systems as a result of chronic disease is substantial. To manage demand on healthcare there has – among others – been an increasing focus on self-management and on the responsibility patients, and their social network, have for health. There is evidence that health literacy skills are important for, and strongly related to, health and self-management (Barry and D'Eath, 2013; Federman et al., 2014; Gazmararian et al., 1999; Heijmans et al., 2014; Inoue et al., 2013; Lai et al., 2013; Sudore, et al., 2006; Van der Heide et al., 2014). Health literacy refers to a broad range of characteristics and personal as well as social resources people need to access, understand, evaluate and communicate information to make decisions about health (Beauchamp et al., 2015; Begoray and Kwan, 2011). Low health literacy may have adverse consequences on health by limiting patients' ability to comprehend health information and find the healthcare they need, for instance because they experience difficulty in communicating with healthcare professionals.

Health literacy does not only include skills needed in healthcare settings. Health literacy is a resource that is integrated in people's everyday lives; health literacy includes information and decision-making skills that are needed in a range of different contexts, such as the supermarket where people choose their food, and in social settings where lifestyle is reinforced (Nutbeam, 2000; Osborne et al., 2013; Peerson and Saunders, 2009). People are embedded in different social contexts, as they belong to families, different communities, and different population groups. These different social contexts can provide resources and support that can help people overcome the difficulties caused by a lack of health literacy skills. It has been suggested that the negative impact of low health literacy can be buffered through the transmission of health information within social networks and communities (Lee et al., 2004). Access to health information can help people with chronic illness to make informed decisions about health and self-management aspects, such as lifestyle. Furthermore, health-promoting behavioural norms in different social contexts may compensate for the negative impact of low health literacy if they help people to adopt healthy behaviours (Lee et al., 2004). Health literacy research, however, often treats people as isolated actors, independent of support and resources in their social environment (Lee et al., 2004; Guzys et al., 2015).

One of the social contexts that can possibly contribute to health and self-management is the neighbourhood. There are differences between areas, such as neighbourhoods, in the health of their inhabitants (Diez Roux, 2001; Diez Roux and Mair, 2010; Lomas, 1998; Pickett and Pearl, 2001; Subramanian et al., 2003). These health differences are related to social capital (Islam et al., 2006; Gilbert et al., 2013; Hunter et al., 2011; Subramanian et al. 2003, Sundquist and Yang 2007, Vyncke et al., 2013). Neighbourhood social capital develops through social relations within the community, and through these relationships resources can be generated (Coleman, 1988). It has been proposed that people have better access to health information in neighbourhoods with more social capital (Kawachi et al., 1999, Kawachi et al., 2007), through contact with neighbours with new or other sources of information.

Furthermore, it has been suggested that in neighbourhoods with more social capital informal social control can be exerted over unhealthy behaviour (Kawachi et al., 1999; Kawachi et al., 2007), such as smoking or excessive drinking. The relationship between social capital and health might differ according to health literacy levels. It might for instance be possible that neighbourhood resources are especially beneficial for people with chronic illness with low health literacy skills needed to otherwise gain access to health information and apply this to their own life. On the other hand, it is possible that higher levels of health literacy skills are needed to access and use neighbourhood resources to promote health. To date there are no studies investigating the beneficial effects of neighbourhood social capital for people with different health literacy levels. Previous studies have examined the effect of individual social support among people with different health literacy levels. These studies show mixed results (Johnson et al., 2010; Lee et al., 2006; Lee et al., 2009). In the study by Johnson et al., (2010) social support was only positively to medication adherence among people with adequate health literacy, and not among people with low health literacy. Lee et al., (2006) found that there was a relationship between health and two types of social support – medical information and healthy reminder support (for example, reminders to take medication or to follow dietary restrictions) – in both low and high health literacy groups. Another study found that the relationship between social support and health was more pronounced for those with high health literacy (Lee et al., 2009).

Abovementioned studies did not find conclusive evidence for the hypothesized interaction between social support and health literacy skills. These studies have all focused on functional health literacy skills (such as reading) (Johnson et al., 2010; Lee et al., 2006; Lee et al., 2009) and did not include a broader range of personal and social dimensions of the health literacy concept.

To date it is unclear how social capital contributes to health of people with chronic illness (Waverijn et al., 2014). It is relevant to study whether neighbourhood social capital can possibly compensate for the negative effect of relatively low health literacy skills on health of people with chronic illness, or whether health literacy enhances the effect of neighbourhood social capital. We will investigate the relationship between neighbourhood social capital and various health literacy skills and examine whether social capital is differentially related to health for people with chronic illness according to health literacy skills. Because social capital can benefit the transmission of information in neighbourhoods and can stimulate people to adopt healthy behaviours (Aarts et al., 2010; Fisher et al., 2004; Kawachi et al., 1999; Kawachi et al., 2007), we specifically focus on those health literacy domains that relate to the ability to access and understand health information and to the ability to perform self-management and lead a healthy lifestyle.

We hypothesize that:

Hypothesis:

There is an interaction between neighbourhood social capital and health literacy skills that has an effect on the health of people with chronic illness.

Methods

Data

National Panel of the Chronically ill and Disabled

Participants for the study are members of the 'Nationaal Panel Chronisch zieken en Gehandicapten' (National Panel of the Chronically ill and Disabled or NPCD). This is a nationwide representative prospective panel study in The Netherlands, established to gather information on the consequences of chronic disease and disability from a patient perspective. For the NPCD, participants are recruited

from random samples of general practices that are drawn from the Dutch Database of General Practices. They are selected using the following criteria: diagnosis of a somatic chronic disease by a certified medical practitioner, aged >15 years, not permanently institutionalized, aware of the diagnosis, not terminally ill (life expectancy >6 months according to their general practitioner), mentally capable of participating, and sufficient mastery of Dutch. The NPCD consists of more than 3,500 people with chronic illness or physical disability. The NPCD is registered with the Dutch Data Protection Authority; all data are collected and handled in accordance with the privacy protection guidelines of this Authority. Panel members fill in questionnaires at home twice a year, either by mail or by internet. In 2014 a questionnaire was sent to 2,375 people with chronic illness and completed by 1,811 people (response rate 76.3%). Non-response analyses showed that people with chronic illness who filled in the questionnaire were on average older than non-responders and more often had comorbidity. Non-responders did not live in different neighbourhoods than responders, in terms of urbanity, neighbourhood social capital and neighbourhood socioeconomic status.

Main variables

Self-rated health

Self-rated health was assessed with the scale 'perceived general health' from the RAND-36 short-form health status survey. In the RAND-36 survey respondents are asked to answer the following question: "In general how would you say your health is?" with answers on a 5-point scale, ranging from 'excellent' to 'poor'. Respondents then select answers that best describe how much they agree with four statements about their health on a 5-point scale ranging from 'totally agree' to 'totally disagree'. The statements are: "I seem to get sick a little easier than other people", "I am as healthy as anybody I know", "I expect my health to get worse" and "My health is excellent". The scale score of perceived general health is the sum of these five items, rescaled to range from 0 (worst health) to 100 (best health) (Van der Zee and Sanderman, 1993). A higher score reflects better perceived general health. In our study, Cronbach's alpha of the scale was 0.80, indicating a high internal consistency. The correlation of this scale with objective health measures and physician-assessed health is high (Simon et al., 2005).

Neighbourhood social capital

Social capital inheres in the social structure in the community and develops through repeated interactions among neighbours. Therefore, neighbourhood social capital was measured by five questions on contacts among neighbours:

- contact with direct neighbours;
- contact with other neighbours;
- whether people in the neighbourhood know each other;
- whether neighbours are friendly to each other; and
- whether there is a friendly and sociable atmosphere in the neighbourhood.

Response categories were 'totally agree', 'agree', 'neutral', 'don't agree', and 'totally don't agree' (thus ranging from 1 to 5). Variables and the resulting scales were coded so that higher values indicate more social capital. We applied econometric analysis, using a three-level hierarchical model (Raudenbush and Sampson, 1999; Raudenbush, 2003), to aggregate the measurement of social capital to the neighbourhood level. We followed the approach described by Mohnen et al. (2011), and adjusted for differences between individuals within neighbourhoods by including sex, age, education, income, employment status, home ownership and years of residence. The highest two levels of the model can be viewed as a multivariate model for the latent true scores, with the lowest level serving as a measurement model (Raudenbush et al., 1991). By aggregating individual responses to the neighbourhood level by using the econometric method, we adjusted for differences in the number of respondents per neighbourhood. Furthermore, by including the items that measure social capital, the model parameterizes the measurement error variation and takes into account item difficulty based on individual response patterns. Variance can be partitioned into three components: variation among neighbourhoods, variation among individuals, and variation within individuals among items used for the social capital measure. We constructed a social capital measure based on the variation among neighbourhoods. This neighbourhood level variable approximately follows a normal distribution and indicates the degree to which neighbourhood social capital differs from the grand mean. A positive score means a higher level of social capital than average. The reliability of the social capital measure depends on the number of items in the scale, the inter-correlation among the items at the individual level, the level of agreement among individuals with a neighbourhood, and the number of individuals within a neighbourhood. The reliability of our social capital measure on the neighbourhood level was 0.74. A value above 0.60 is considered to be adequate (Mossey and Shapiro, 1982).

In our study neighbourhoods are spatially defined based on 4-digit postal codes. Postal codes in the Netherlands are used to identify relatively small geographical areas that comprise between 1–8 km² with an average of approximately 4000 residents per postal code area. In urban regions, these areas correspond with urban neighbourhoods; in rural regions, they may encompass small villages.

Housing and living survey

Information about neighbourhood social capital was acquired through WoOn, the 'Housing and Living Survey 2012', commissioned by the Ministry of the Interior and Kingdom Relations. WoOn 2012 is representative of residents of the Netherlands of 18 years and above. The data were collected among 69,336 people between September 2011 and May 2012 (response rate of 58%) in 3425 neighbourhoods with an average of 20 respondents per neighbourhood. Statistics Netherlands provided us with access to data of neighbourhoods that had a minimum of three respondents; resulting in a dataset containing 2,544 neighbourhoods with an average of 27 respondents per neighbourhood. Data was collected by telephone, face to face interviews and internet. Participants were randomly selected from the population of Dutch households with at least one person aged 18 years or above.

We used the postal code of the residential address of people with chronic illness to add the information on neighbourhood social capital to the dataset containing information on self-rated health and health literacy.

Health literacy

To measure health Literacy we used four scales of the Health Literacy Questionnaire (HLQ) developed by Osborne et al. (2013). The complete HLQ measures nine distinct domains of health literacy skills based on 44 questions. For 23 of the 44 items people were asked to state to what degree they agree with a statement (for instance: "I compare health information from different sources"). These items were answered on a four-point likert scale with answer categories: 'Strongly disagree', 'Disagree', 'Agree', 'Strongly agree'. For the other 21 of the of the 44 items, people were asked how easy or difficult a number of tasks were for them (for instance: "Ask healthcare providers questions to get the health information you need"). These items were answered on a five-point likert scale with the answer categories: 'Cannot do', 'Very difficult', 'Quite difficult', 'Quite easy', 'Very easy'. We used the Dutch version of the HLQ that is translated and

validated by Heijmans et al. (in preparation). To construct scale scores for the health literacy scales, we applied the same approach as described above for the construction of the social capital measure. We used a two-level model, with the lowest level serving as the measurement model, to create scores for the four health literacy domains used in our study ('having sufficient information to manage my health'; 'actively managing my health'; 'ability to find good health information'; and 'understanding health information well enough to know what to do'). The model takes into account item difficulty based on item characteristics and individual response patterns, and parameterizes the measurement error variation attributable to item inconsistency. Variance in scores on scales of the HLQ can be partitioned into variation among individuals, and variation within individuals among items used for the construction of the health literacy scales. The measure of health literacy was based on the individual level deviation of the sample mean and approximately follows a normal distribution. The reliability of the health literacy scales varied, depending on the scale, between 0.77 and 0.89.

Compensatory health literacy skills

If health literacy domains comprise different skillsets it is possible that people with chronic illness compensate for low health literacy skills in one domain with skills in other health literacy domains. Some of the health literacy domains in our study showed considerable overlap. Pearson correlation between the scales 'ability to find good health information' and 'understanding health information well enough to know what to do' was 0.81. However, there were also distinct differences between the health literacy domains and the skills they measure. The scales 'ability to manage health' and 'understanding health information well enough what to do' had a Pearson correlation of 0.23. It is possible that people with relatively low health literacy in a specific domain compensate with health literacy skills in other domains. Therefore, in each of the four models we included information on peoples' health literacy skills in the other three domains of the HLQ we use in this study. To construct such a compensatory measure we used Principal Components Analysis (unrotated), which showed that health literacy skills in the *other* three domains mapped onto one component for each of the four health literacy domains (for each domain there was only one component with an eigenvalue greater than 1). These components all had an eigenvalue of 1.9 or higher.

Confounding variables

Urbanity of the neighbourhood

On the neighbourhood level we included the urbanity of the municipality in which a given neighbourhood is located. Urbanity was provided by Statistics Netherlands (CBS) (2015), and was based on the number of addresses per km² (1=Urban=More than 2,500 addresses/km², 2=Semi-urban=1,500-2,499 addresses/km², 3=intermediate urban-rural=1,000–1,499 addresses/km², 4=Semi-rural=500-1000 addresses per km², 5=Rural=Up to 500 addresses per km²).

Socioeconomic status of the neighbourhood

As an indicator of the socioeconomic status of the neighbourhood we used a measure of the average taxable income of all households in a specific neighbourhood, based on information provided by Statistics Netherlands (CBS) (2016). Average taxable income was divided into 4 categories; less than 22,100 euro per year, between 22,101 and 30,000 euro per year, between 30,001 and 35,739 euro per year, and more than 35,739 euro per year. Single households with a taxable income of less than 22,100 euro per year are eligible to receive rent subsidy and have priority for low-rent housing. In the analyses we included the percentage of households per neighbourhood with a taxable income less than 22,100 euro per year.

Demographic characteristics

We included a number of individual characteristics of people with chronic illness, namely: sex; age, measured in years in 2014; educational level, coded as either low (no education until the lowest high school degree), intermediate (vocational training and the highest two high school degrees), high (university of applied sciences degree and university degree); living status (living alone or living together with a partner or children); and net equivalent income. Net equivalent income was defined as the sum of the monthly net incomes of all household members corrected for household composition (Siermann et al., 2004). Rijken and Groenewegen (2008) found that social deprivation mediated the negative relationship between income and life satisfaction of people with chronic illness. Because social deprivation might also be relevant for self-rated health, we included a measure of social deprivation in our analyses. Social deprivation can be defined as a situation in which people are constrained in their social functioning because of a lack of financial means. Social deprivation is assessed by a deprivation measure described by Van Agt et al. (2000) consisting of seven

items (see Rijken and Groenewegen (2008) for the specific items). Because the presumed negative effect of social deprivation on health is likely to increase when people experience a higher level of social deprivation, we constructed a count variable based on the number of domains in which people are constrained because of a lack of financial means.

Illness characteristics

We also include a number of illness characteristics of people with chronic illness, namely: the nature of the first diagnosed chronic disease (including cardiovascular diseases, cancer, respiratory diseases, diabetes, musculoskeletal diseases, neurological diseases and digestive diseases) as reported by the general practitioner; number of chronic diseases (ranging from '1' to '4 or more'); and the presence and severity of physical disabilities (no physical disabilities, mild, moderate or severe physical disabilities) as assessed by a validated Dutch questionnaire containing questions about the ability to perform a number of activities in daily life (De Klerk et al., 2003).

Analysis

Descriptive statistics were applied to describe our sample according to demographic characteristics and to describe the distribution of the dependent and independent variables in our sample. Using Stata's module to run MLwiN 2.24 through Stata, we conducted multilevel linear regression analyses with patients nested in neighbourhoods. We conducted interaction analyses to examine whether the relationship between neighbourhood social capital and health differs according to health literacy skills in four domains. First we examined the effect of neighbourhood social capital on health without taking into account health literacy skills, second we described the effect of health literacy skills on health without taking into account neighbourhood characteristics. Consequently, we ran four models, each focusing on a different health literacy domain. For each model, in the first step we included social capital and the main effect of skills in a specific health literacy domain on health. In the second step we also included the interaction between social capital and health literacy. In all four models we included the compensatory health literacy skills people possess as well as a number of confounding variables, on the neighbourhood level and on the individual level. To enhance interpretability of

the results, we centred the variable ‘age’, ‘income’ and ‘percentage of households with an income lower than 22,100 per neighbourhood’. Variance inflation factors were examined for each variable included in the regression models. None of the regression models displayed signs of multicollinearity. Variance inflation factors in our models are all lower than 4, whereas values of 4 or 10 are often used as cut-off points indicating multicollinearity (O’Brien, 2007).

Results

Sample characteristics

Table 7.1 displays sample characteristics. A little more than half of the people in our sample was female (53%) and mean age was 63 years. About a third of the respondents had a low educational level and a quarter of the respondents lived alone. Net equivalent income was €1,490 per month. More than half of the respondents had multiple chronic diseases and around one third of the respondents experienced moderate or severe disabilities. Average perceived general health in our sample was 51 points on a scale of 1-100. This is lower than average perceived general health of the Dutch population (73 points on a scale of 1-100) (Van der Zee et al., 1993). The average health literacy scores of people with chronic illness are also presented in table 7.1.

Table 7.1 Descriptive statistics of sample of people with chronic illness in 2014

| | |
|--------------------------------|-------------|
| | Percent |
| <i>Sex: (n=1811)</i> | |
| male | 46.7 |
| female | 53.3 |
| | Mean (sd) |
| <i>Age in years (n=1811)</i> | 62.9 (14.0) |
| | Percent |
| <i>Education: (n=1767)</i> | |
| low | 31.8 |
| intermediate | 43.2 |
| high | 25.0 |
| <i>Living status: (n=1798)</i> | |
| living alone | 24.5 |
| living together | 75.5 |

- table 7.1 continues -

- table 7.1 continued -

| | | Mean (sd) |
|--|-------|------------------|
| <hr/> | | |
| <i>Net equivalent income</i> (n=1524) | | €1489.70 (585.8) |
| <hr/> | | |
| | | Percent |
| <i>Social deprivation domains:</i> (n=1656) | | |
| 0 | | 67.6 |
| 1 | | 10.5 |
| 2 | | 6.6 |
| 3 | | 4.7 |
| 4 | | 4.1 |
| 5 | | 2.9 |
| 6 | | 2.4 |
| 7 | | 1.2 |
| <i>First diagnosed chronic disease:</i> (n=1811) | | |
| cardiovascular disease | | 15.6 |
| respiratory disease | | 37.3 |
| musculoskeletal disease | | 10.4 |
| cancer | | 4.8 |
| diabetes | | 11.0 |
| neurological disease | | 5.0 |
| digestive disease | | 4.1 |
| other disease | | 11.9 |
| <i>Number of chronic diseases:</i> (n=1811) | | |
| one | | 46.8 |
| two | | 30.7 |
| three | | 13.9 |
| four or more | | 8.6 |
| <i>Presence and severity of disability:</i> (n=1713) | | |
| no disability | | 37.8 |
| mild disability | | 28.5 |
| moderate disability | | 25.0 |
| severe disability | | 8.7 |
| <hr/> | | |
| | Range | Mean (sd) |
| <i>Perceived general health</i> (n=1788) | 0-100 | 50.8 (20.4) |
| <i>Health literacy</i> | | |
| having sufficient information to manage my health (n=1750) | 1-4 | 2.90 (0.42) |
| actively managing my health (n=1752) | 1-4 | 2.84 (0.43) |
| ability to find good health information (n=1755) | 1-5 | 3.91 (0.63) |
| understanding health information well enough to know what to do (n=1752) | 1.4-5 | 4.02 (0.58) |
| <hr/> | | |

Average social capital of the neighbourhoods in our sample was a little below average social capital of other Dutch neighbourhoods in the WoOn-dataset (a score of zero means exactly average) (table 7.2). Most people in our sample lived in semi-urban neighbourhoods or semi-rural neighbourhoods. On average a quarter of the households in a neighbourhood (26%) had a taxable income lower than 22,100 euro per year.

Table 7.2 Descriptive statistics of neighbourhood level variables

| | Range | Mean (sd) |
|---|------------------------|----------------------------|
| <i>Neighbourhood social capital</i> (n=592) (year=2012) | -0.43 – 0.25 | -0.01 (0.10) |
| | | Percent |
| <i>Urbanity</i> (n=651) | | |
| urban | | 13.21 |
| semi-urban | | 31.95 |
| intermediate urban-rural | | 23.81 |
| semi-rural | | 21.66 |
| rural | | 9.37 |
| | Range (percentages) | Mean (sd) (percentages) |
| <i>Neighbourhood socio-economic status</i> (n=641) (year=2013) | | |
| income lower than 22100 | 6-70 | 26.19 (10.09) |
| income between 22101 and 30000 | 2-22 | 13.68 (2.92) |
| income between 30001 and 35739 | 3-14 | 8.73 (1.39) |
| income higher than 35739 | 10-89 | 51.37 (12.27) |

Relationship between social capital, health literacy and health

When examining the effects of health literacy skills in a specific domain (without taking into account health literacy skills in the other three domains), health literacy skills in three out of four domains were positively related to self-rated health (table 7.3). Health literacy skills in the domain ‘actively managing health’ were not significantly related to health.

Table 7.3 Regression analyses of the relationship between health literacy skills and health, four separate models for each of the health literacy domains

| | <i>Chronic illness self-management</i> | |
|---|--|-----------|
| | Coef. (std.err) | |
| <i>Model 1 (n=1258)</i> | | |
| intercept | 66.32 | (2.19)*** |
| having sufficient information | 10.89 | (1.54)*** |
| <i>Model 2 (n=1257)</i> | | |
| intercept | 65.67 | (2.24)*** |
| actively managing health | 2.11 | (1.53) |
| <i>Model 3 (n=1267)</i> | | |
| intercept | 66.10 | (2.20)*** |
| ability to find good health information | 5.05 | (1.02)*** |
| <i>Model 4 (n=1266)</i> | | |
| intercept | 66.38 | (2.22)*** |
| understanding health information | 5.17 | (1.13)*** |

Note: Analyses controlled for age, educational level, living status, net equivalent income, social deprivation, first diagnosed chronic diseases, number of chronic diseases, and presence and severity of disability.

* $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.001$

Social capital was significantly related to health (all models, step 1, table 7.4). The relationship between social capital and health, was also significant when excluding health literacy skills from the model (coefficient of social capital in a model without health literacy skills=1.32, std. error=0.61, $p=0.032$) (not in table). When simultaneously considering skills in other health literacy domains, instead of only looking at one type of health literacy skills in isolation, only skills in the domain ‘having sufficient information’ were significantly related to health (all models, step1, table 7.4).

There was a significant positive interaction between neighbourhood social capital and health literacy skills in the domains ‘ability to find good health information’ and ‘understanding health information well enough to know what to do’ (model 3 and model 4, step 2, table 7.4). There was no interaction between neighbourhood social capital and health literacy skills in the other two domains (Model 1 and Model 2, step 2, table 7.4).

Table 7.4 Multilevel regression analyses of neighbourhood social capital, health literacy domains and self-rated health, (Ni=1173, Nj=482)^a, 2014

| Self-rated health 2014 | Model 1 | | Model 2 | | Model 3 | | Model 4 | |
|--|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|--------------------|
| | Step 1 | Step 2 |
| | B (SE) |
| Intercept | 67.50 (2.69)*** | 67.34 (2.69)*** | 67.68 (2.70)*** | 67.81 (2.70)*** | 67.83 (2.70)*** | 67.72 (2.70)*** | 67.74 (2.70)*** | 67.67 (2.70)*** |
| Social capital | 1.57 (0.61)** | 1.61 (0.61)** | 1.61 (0.61)** | 1.51 (0.62)* | 1.61 (0.61)** | 1.61 (0.61)** | 1.61 (0.61)** | 1.62 (0.61)** |
| Health Literacy – Having sufficient information | 10.33 (1.96)*** | 10.45 (1.96)*** | | | | | | |
| Interaction social capital * Having sufficient information | | 2.35 (1.48) | | | | | | |
| Health Literacy - Actively managing my health | | | -0.38 (1.61) | -0.54 (1.62) | | | | |
| Interaction social capital * Actively managing my health | | | | -2.06 (1.48) | | | | |
| Health Literacy - Ability to find good health information | | | | | 1.32 (1.41) | 0.85 (1.42) | | |
| Interaction social capital * Ability to find good health information | | | | | | 2.07 (0.91)* | | |
| Health Literacy - Understanding health information | | | | | | | 0.98 (1.46) | 0.79 (1.46) |

| Self-rated health 2014 | Model 1 | | Model 2 | | Model 3 | | Model 4 | |
|---|----------------|----------------|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|
| | Step 1 | Step 2 | Step 1 | Step 2 | Step 1 | Step 2 | Step 1 | Step 2 |
| | B (SE) | B (SE) | B (SE) | B (SE) | B (SE) | B (SE) | B (SE) | B (SE) |
| Interaction social capital * | | | | | | | | 2.04 |
| Understanding health information | | | | | | | | (0.97)* |
| Health literacy skills in other domains | 0.35 (0.50) | 0.33 (0.50) | 2.35 (0.40)*** | 2.36 (0.40)*** | 2.05 (0.55)*** | 2.16 (0.55)*** | 2.18 (0.51)*** | 2.21 (0.51)*** |
| Variance neighbourhood level (SE) | 8.51 (6.38) | 8.19 (6.30) | 7.59 (6.22) | 7.65 (6.22) | 7.72 (6.25) | 7.40 (6.15) | 7.65 (6.22) | 6.97 (6.05) |

Note. Analyses controlled for age, educational level, living status, net equivalent income, social deprivation, first diagnosed chronic diseases, number of chronic diseases, presence and severity of disability, urbanity, and socio-economic status of the neighbourhood.

* p<0.05; ** p<0.01; *** p<0.001

^a Ni=number of individuals, Nj=number of neighbourhoods

Discussion

We found that there is a positive effect of neighbourhood social capital on health of people with chronic illness, and that the effect of neighbourhood social capital is stronger for people with better health literacy skills to find and understand health information - whilst taking into account compensatory skills in other domains. The results of this study suggests that whether people with chronic illness can access and use neighbourhood resources, such as health information or health promoting behavioural norms, to benefit health might depend on the health literacy skills they have. It is possible that social capital cannot offer compensatory resources, because a low level of skills needed to access and understand health information might hinder access to neighbourhood resources or inhibit people with chronic illness to use these resources to benefit health.

There is no relationship between health and health literacy in the domain 'actively managing health'. This health literacy domain consists of a measure that does not tap into specific aspects of self-management.

Health literacy in the domains 'actively managing health' and 'having sufficient health information' did not show an interaction with neighbourhood social capital. The difference between these two domains and the other two domains, that did interact with neighbourhood social capital, is that these two domains are much more focused on people's current behaviours and circumstances, whereas the other two domains are more related to the general presence of certain skillsets. With regard to health literacy in the domain 'actively managing health', it is possible that a more task-specific measure of health literacy is needed to gain insight into the relationship between health literacy, health and neighbourhood social capital. For instance, the positive effect of social control over unhealthy behaviour in neighbourhoods might be enhanced by health literacy skills specifically needed for lifestyle and behaviour changes.

There are no previous studies investigating the relationship between neighbourhood social capital and health literacy. Furthermore, previous studies investigating the relationship between social support and health literacy, have operationalized health literacy as basic reading comprehension and pronunciation skills, by using the Rapid Estimate of Adult Literacy in Medicine instrument (Davis et al., 1991) or the Test of Functional Health Literacy in Adults (Parker et al., 1995). We studied the relationship between health literacy, health and neighbourhood social capital by using the Health Literacy

Questionnaire (HLQ, Osborne et al., 2013). The HLQ is a comprehensive measurement of health literacy encompassing various skills and a broad range of resources.

As previously mentioned, in our study neighbourhoods are spatially defined based on 4-digit postal codes. There is discussion on the relevant scale to measure the neighbourhood (see for instance: Bader and Ailshire, 2014). Neighbourhoods can, for instance, be spatially defined based on key area codes (Lochner et al., 2003), defined as a zone around the home with a predefined radius (Robertson et al., 2012) or more qualitatively designated by the individual perceptions that residents have of the area around their house (Wen et al., 2003). It is unlikely that people have strong ties or regular contacts with all people in their neighbourhood (Bridge, 2002). However, the transmission of information as well as informal social control are not limited to dense ties or people in the immediate surrounding. Exchange of information benefits from larger networks that are more dispersed and consist of weak ties (Cattell, 2001; Granovetter, 1973). The people we have weak connections with (for instance people in our neighbourhood) are more likely to move in circles different from our own and will thus have access to information different from that which we receive. The social capital measure we used was based on questions about contacts with neighbours, but we had no information on specific neighbourhood networks and the nature of social ties in the neighbourhood.

There are a number of challenges to the generalizability of our results. We send our questionnaire to a group of people with chronic illness representative for the Dutch population of people with chronic illness. However, respondents were on average older and more often had comorbidity than non-respondents. It is possible that our sample has a higher illness burden than the Dutch population of people with chronic illness, and therefore lower self-rated health. Furthermore, it is possible that we overestimate the level of health literacy in our sample due to the nature of data-collection. It is possible that those people who lack the skills to participate in a written questionnaire, would benefit most from neighbourhood social capital. Therefore we might underestimate the relationship between social capital and health for people with relatively low literacy.

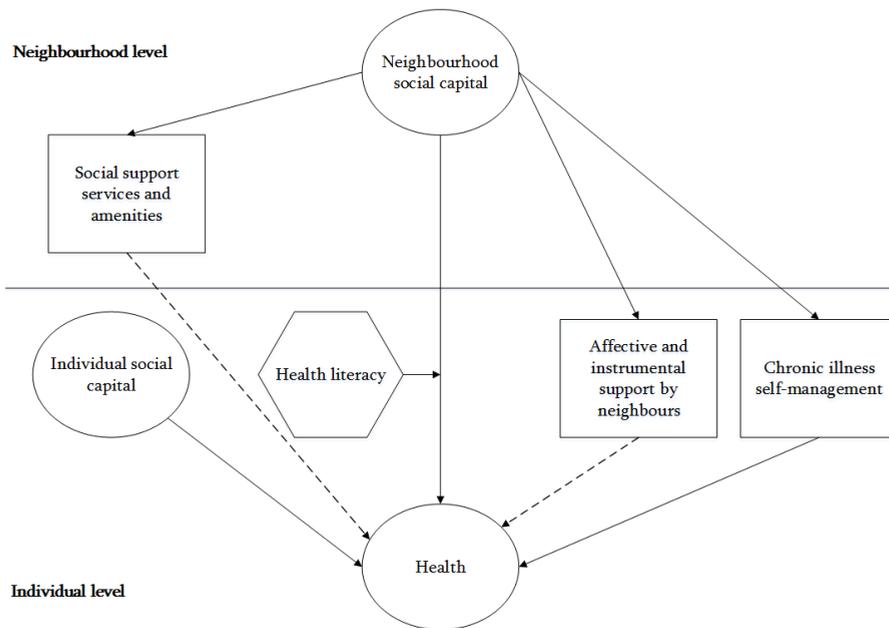
Whether people have sufficient health literacy skills can vary across situations. What health literacy enables people to do depends on the demands placed on them by different contexts (Nutbeam, 2000; Paasche-Orlow and Wolf, 2007).

This means that whether people with chronic illness have sufficient health literacy skills depends on the demands and challenges that they are faced with due to their illness. We do not know how specific health literacy limitations can be compensated by other personal or social resources. In our study the main effect of specific health literacy skills disappeared when taking into account skills in other domains. It is necessary to gain further insight into how different types of health literacy skills interact to benefit health, and which health literacy skills are most important for whom. Furthermore, more research is needed to learn how health knowledge is transferred within communities and how people draw on knowledge, support and guidance from others.

Healthcare professionals should pay specific attention to those who have low health literacy or low capabilities to meet the specific demands of their chronic illness, and who lack the health literacy skills to gain access to and use the social resources and support they need (Lee et al., 2004).

8

Summary of findings and suggestions for future research



This thesis examined the relationship between neighbourhood social capital and health of people with chronic illness.

The main question of this thesis was:

“Is neighbourhood social capital related to health of people with chronic illness? And if so, how can we explain the relationship between neighbourhood social capital and health of people with chronic illness?”

This chapter will summarize the findings of this thesis. Consequently this chapter will reflect on these findings and will offer suggestions for future research. This chapter will end with a conclusion and recommendations for policy.

Summary of findings

Neighbourhood social capital positively influences changes in health of people with chronic illness

We found that both neighbourhood social capital and individual social capital have a positive effect on changes in health of people with chronic illness. Neighbourhood social capital refers to the web of relationships between people in a community. At the individual level social capital refers to resources generated in the relationship between specific individuals. Our results imply that neighbourhood social capital can also benefit people with chronic illness who lack relationships with specific individuals in their neighbourhood. This means that even people who rarely interact with their neighbours, might benefit from living in a neighbourhood where people know each other. This finding is relevant for people with chronic illness. People with chronic illness may have limited possibilities to form and maintain social relationships in their neighbourhood, due to the limitations and extra tasks they face as a result of their illness. People with chronic illness may, for instance, be unable to go out and interact with their neighbours because they lack energy or have physical disabilities. They may also be busy with the tasks they are faced with in addition to the roles and responsibilities they fulfil in their daily life, such as exercising and regular medical appointments. The following studies in this thesis were

aimed at gaining insight into why people with chronic illness are in better health if they live in a neighbourhood with more social capital.

Neighbours make valuable but limited contributions to health and self-management of people with chronic illness

We conducted a qualitative study to gain more insight into the way neighbours, and other social network members, contribute to health and self-management from the perspective of people with chronic illness. Results of this study showed that neighbours mainly contribute to self-management by providing support for practical work in and around the home, such as household maintenance, garden work, and chores such as unloading groceries from the car. These contributions are instrumental in facilitating chronically ill people to live in their own home. The unique quality of relationships with neighbours is that they are close by and can easily help if an unforeseen situation comes up or action needs to be taken quickly. People with chronic illness describe elements of distance in their relationships with neighbours. This means that there is a limit to the support that neighbours want to give or that people with chronic illness would be comfortable accepting from neighbours. Neighbours are rarely involved in medical care, or more private tasks, such as bathing and nursing tasks. Other research also confirms that neighbourhood relationships simultaneously involve elements of friendly distance, supportiveness, and a maintenance of exclusive boundaries and a focus on privacy (Crow et al., 2002). This differentiates neighbourhood relationships from friendships, which are chosen relationships and sources of emotional and moral support. Our results suggest that, from the perspective of people with chronic illness, it is unrealistic to expect that people in the neighbourhood will always be able to offer sufficient support when other sources of support are unavailable. In general, there may be limits to support people with chronic illness can get in their neighbourhood.

Mechanisms behind the relationship between neighbourhood social capital and health of people with chronic illness

In the following studies of this thesis we investigated a number of mechanisms behind the relationship between neighbourhood social capital and health of people with chronic illness.

No evidence for increased provision of municipal services and amenities as a mechanism behind the relationship between neighbourhood social capital and health of people with chronic illness

People with chronic illness may benefit from access to municipal services and amenities that are aimed at promoting self-sufficiency and well-being. We posited that neighbourhood social capital may improve access to these services and amenities. Neighbours that are more connected may be more likely to come together and advocate access to health-promoting resources in their neighbourhood. The extent to which community members are willing to work for common goals and want to intervene on behalf of the common good is known as collective efficacy. It has been stated that neighbourhood social capital fosters the development of collective efficacy and cooperative behaviour (Collins et al., 2014; Kawachi et al., 1999; Kawachi and Berkman, 2000). One of the goals that people in a neighbourhood can collectively work for is the provision of services and amenities that can benefit health. The situation in the Netherlands provided a good case to study the relationship between social capital, collective efficacy and the provision of services and amenities. In the Netherlands municipalities carry the responsibility for developing a coherent local social support policy for people who experience limitations to their participation in society (Kroneman et al. 2012; Schäfer et al. 2010). We studied the relationship between neighbourhood social capital in municipalities, collective efficacy and three types of services and amenities that municipalities provide; namely services to support informal caregivers, the individual services and support that the municipality provides (e.g. domiciliary help, adaptation of the house and meal supply), and the general and collective services and amenities provided by municipalities (e.g. lending point for wheelchairs and mobility scooters, collective transport facilities and sports facilities for disabled people). We did not find evidence that social capital and collective efficacy in municipalities were related to increased provision of services and amenities by municipalities. We did find that social capital and collective efficacy were related to the provision of support services for informal caregivers in rural municipalities.

Neighbourhood social capital does not provide access to instrumental and affective support by neighbours

The results of the qualitative study indicated that neighbours provide valuable support for people with chronic illness, mainly through practical help with work or chores in and around the home. We posited that in a neighbourhood with

more social capital there might be more of a general tendency to help each other (for instance with work in the garden, carrying groceries, or by having a conversation on the street), even when people don't know each other very well. However, we found that people who live in neighbourhoods with more social capital are not more likely to receive support from neighbours if they are not personally connected to others in their neighbourhood. Only those people who know their neighbours well, will receive support from them. Our results confirm what Carpiano (2006; 2008) stated, namely that the some benefits of social capital are generally restricted to individuals who are part of the network that generates these resources. Some resources provided through neighbourhood social capital might benefit all residents in a neighbourhood, such as increased safety due to informal social control in a neighbourhood (Sampson et al., 1997). Other resources, such as social support, might only benefit people who can access these resources through personal connections to neighbours.

Neighbourhood social capital benefits self-management of people with chronic illness and mild physical disabilities

We posited that the resources provided through neighbourhood social capital might benefit chronic illness self-management. Chronic illness self-management is a multidimensional concept. It is unlikely that resources generated in the neighbourhood are illness specific, and provide information that is relevant for specific medical tasks or complex medication regimes. However, people with chronic illness may use neighbourhood resources for self-management tasks such as maintaining a healthy lifestyle or dealing with the emotional consequences of a chronic illness. Our results showed that there is a relationship between neighbourhood social capital and self-management of people with chronic illness with mild physical disabilities. It is possible that neighbourhood resources do not benefit self-management of people without physical disabilities as they experience few self-management challenges and are not in need of neighbourhood resources to improve self-management. The presence of moderate or severe physical disabilities on the other hand severely hinders coping with the consequences of a chronic disease. It is possible that neighbourhood social capital does not provide resources for people with chronic illness with moderate or severe physical disabilities. People with chronic illness and mild disabilities might for instance benefit from increased access to information about exercise and an active lifestyle, whereas people with moderate

or severe physical disabilities are unable to benefit from generic information about exercise programs.

No evidence that increased access to information provided by neighbourhood social capital can compensate for limited health literacy skills of people with chronic illness

People with chronic illness need to access, understand and apply health information to make decisions about health, for instance about the symptoms they experience, healthcare, medication or lifestyle changes. We hypothesized that neighbourhood social capital may benefit health of people with chronic illness through increased access to health information (Kawachi et al., 1999; Kawachi et al., 2007). They might for instance receive information about healthy food outlets nearby or exercise groups that they can join. They might also hear about healthy recipes, supplements that might benefit their health or a good physical therapist that just opened up a practice. People with chronic illness may have increased access to health information in neighbourhoods with more social capital, as the diffusion of information is likely to benefit from contacts between weak ties such as neighbours (Cattell, 2001; Granovetter, 1973). People with whom individuals have weak connections – such as neighbours – are more likely to move in different circles and will thus have access to information that is different from the information people will receive from close ties. We investigated whether increased access to health information in the neighbourhood would especially benefit those people with chronic illness that had limited health literacy skills needed to access, understand, evaluate and communicate information to make decisions about health (Beauchamp et al., 2015; Begoray and Kwan, 2012). People with low health literacy may have difficulty finding healthcare and services that they need and difficulty finding and understanding health information. People with low health literacy might especially benefit from information that they come across in their neighbourhood that they otherwise would not have had access to. However, we posited that it is also possible that health literacy skills are needed to access and use neighbourhood resources to promote health. We found that neighbourhood social capital does not compensate for limited health literacy skills, but especially benefits people with chronic illness that have better health literacy skills to access and understand health information. These results suggest that differences in health literacy skills may cause inequality between people in the way they can access and use neighbourhood resources.

Theoretical reflections

This thesis aimed to gain insight in the importance of neighbourhood social capital for people with chronic illness by focusing on a number of possible mechanisms behind the relationship between neighbourhood social capital and health. We did not find conclusive evidence for any of the mechanisms studied in this thesis. In the next part of this chapter I will reflect on a number of theoretical issues that may explain the lack of evidence for specific pathways behind the relationship between neighbourhood social capital and health of people with chronic illness.

Heterogeneous effects of neighbourhood social capital

The results of the studies in this thesis indicate that the effect of neighbourhood social capital on health of people with chronic illness is by no means homogenous across different subgroups. We found that:

- Neighbourhood social capital benefits people with high literacy skills to access and understand health information.
- Neighbourhood social capital and collective efficacy are not (yet) related to the increased provision of municipal services and amenities, with exception of the provision of support services for informal caregivers in rural municipalities.
- Neighbourhood social capital is related to chronic illness self-management only for people with mild physical disabilities.

Although treated as one population group in this thesis, the group of people with chronic illness is by no means homogeneous. There is great variety in the type of chronic illness and the associated, personal as well as medical, burden. It is possible that the hypotheses we formulated with regard to the relationship between neighbourhood social capital and health of people with chronic illness did not properly take into account the heterogeneity of the group of people with chronic illness. We did take into account a number of demographic and disease characteristics whilst studying the relationship between neighbourhood social capital and health of people of chronic illness.

Neighbourhood social capital as a public good that is available to people with chronic illness in a neighbourhood?

In this thesis we aimed to identify pathways behind the relationship between neighbourhood social capital and health, based on the assumption that

neighbourhood social capital provides collective resources that are available to all chronically ill residents of a neighbourhood. However, we might not have been able to find evidence for many of our hypotheses because we did not consider differences in individual ability of people with chronic illness to draw upon the resources provided by neighbourhood social capital. People with chronic illness who are personally less connected to their neighbours may benefit from neighbourhood social capital in different ways. They can, for instance, benefit from living in a community where people watch each other's kids or where people check to see if help is needed when someone hasn't been out of the house for a long time. However, we have already posited that it is possible that specific resources (such as affective and instrumental support from neighbours) are not collective in nature but are only accessible through individual personal connections to others in the neighbourhood. Bourdieu emphasizes the importance of individual network connections that people can effectively mobilize to access specific resources (Bourdieu, 1986). We also found that neighbourhood social capital benefits people with chronic illness with better health literacy skills to access and understand health information. This suggests that neighbourhood social capital mainly benefits people with chronic illness that have the individual skills needed to access, understand and use the resources supplied by neighbourhood social capital. Overall, people with chronic illness may differ strongly in their ability to draw upon neighbourhood resources to reach their goals.

Studying neighbourhood social capital: the necessity of an integrated view of neighbourhood conditions

In the studies conducted for this thesis we have included a few neighbourhood characteristics besides neighbourhood social capital, among which are urbanity and socioeconomic status of a neighbourhood. However, to find evidence for the relationship between neighbourhood social capital and health of people with chronic illness it might be necessary to take into account other (physical and social) characteristics of the neighbourhood. It is possible that the benefit of neighbourhood social capital for health of people with chronic illness depends on neighbourhood socio-demographic and physical conditions as well as the services and amenities present. In some neighbourhoods people with chronic illness might be more dependent on neighbourhood resources than in others. For instance; people with chronic illness who live in neighbourhoods with a park nearby might use that park to take walks or exercise. If they do not have a park

in their vicinity, they might need to draw on neighbourhood social capital. For instance by asking a neighbour to drive them to a park that is further away. Also, if someone with visual impairments is afraid to walk in a poorly lit neighbourhood in the evening, they might need a neighbour to walk with them. In a well-lit neighbourhood they might be able to walk alone, and would thus not need to draw on neighbourhood social capital in the same way. Furthermore, in a neighbourhood with more social services and amenities people with chronic illness might be more likely to use professional support services instead of drawing on support from neighbours. Socioeconomic conditions of a neighbourhood (such as neighbourhood social capital and neighbourhood affluence) may also be integrally linked to the physical conditions. For instance, Clark et al. (2013) state that affluent neighbourhoods are likely to attract a set of services and amenities (e.g. food stores, places to exercise, parks) that promote specific norms (e.g. the importance of a healthy diet and sufficient exercise).

Ruijsbroek et al. also confirm the importance of taking interactions between neighbourhood characteristics into account when examining their relationship with health (Ruijsbroek et al., 2016). They found that improvements in neighbourhood social capital were associated with better health, but that the negative impact of deteriorating neighbourhood safety overruled the positive health impact of improvements in neighbourhood social capital. This means that omitting relevant neighbourhood variables, may cause the health impact of neighbourhood social capital to be over- or underestimated.

Does neighbourhood social capital provide actual or potential resources for health of people with chronic illness?

It is possible that we did not find evidence for the benefit of specific neighbourhood resources for health of people with chronic illness, because we did not have sufficient information on the way people with chronic illness actually use neighbourhood resources. We only had information on whether people with chronic illness received support from neighbours. We did not have information on the actual use of social services and amenities provided by municipalities. We also do not know whether people with chronic illness actually used health information received from neighbours to benefit health. Through the qualitative research conducted for this study we gained insight into the way people with chronic illness view the contributions of their neighbours. However, to find quantitative evidence for the relationship between

neighbourhood social capital and health it might be necessary to include information on the actual use of resources by people with chronic illness. Although we assumed that neighbourhood social capital can benefit health of people with chronic illness because it provides actual resources, it might also be true that neighbourhood social capital benefits health of people with chronic illness because they experience that potential resources are available if they might need them. It is also possible that neighbourhood social capital benefits health and self-management in ways not studied in this thesis. For instance, increased emotional wellbeing in neighbourhoods with more social capital through feelings of safety and respect may help people with chronic illness to gain confidence and overcome barriers to self-management.

Definition of neighbourhood social capital

In this thesis we have chosen to define neighbourhood social capital with a focus on relationships between neighbours. It is possible that we did not find conclusive evidence for a number of the hypotheses tested in this study, because we used a general – non-task specific – measure of neighbourhood social capital. Coleman (1988) however states that social capital is defined by its function. Ties between neighbours can be the source of many different resources that can be used to fulfil different goals. Nevertheless, different resources are not necessarily exchangeable. A specific form of social capital might be valuable to facilitate a certain goal, but might be useless in another situation (Coleman, 1988). For instance, a neighbourhood might have a lot of social capital that provides access to health information, but might not have social capital that leads to collective action to lobby for access to health-promoting services and amenities. We did not take into account that neighbourhoods that are similar in the degree of connectedness between neighbours, can still vary in the specific resources they provide. To gain more insight into the relationship between neighbourhood social capital and health of people with chronic illness, it might be necessary to use a more resource-specific measure of neighbourhood social capital.

Scale of the neighbourhood

It is possible that the neighbourhood scale used in this thesis was not appropriate to gain insight into the relationship between neighbourhood social capital and health. We used the same neighbourhood scale throughout this thesis, namely 4-digit postal codes. However, the appropriate neighbourhood scale to study the relationship between neighbourhood social capital and health may depend on

the mechanism that is being studied. The scale of the neighbourhood might be quite large when it is considered with regard to health promoting services and amenities, but might be quite small when it is based on walkable distance to green space or on the interactions between neighbours. Furthermore, the neighbourhood can be based on definitions that differ between individuals, but can also have fixed boundaries. Hipp (2007) states that it is important that that particular geographic unit is appropriate for the outcome of interest. It is important to refrain from aggregating specific characteristics to units that still contain a considerable amount of heterogeneity among the smaller units comprising them. For instance, within specific postal code areas there may be great variation in social capital between blocks or groups of streets. We did not have the necessary data to aggregate neighbourhood social capital to units that were smaller than postal code areas.

Methodological reflections

Compositional and contextual effects of neighbourhood social capital

A strength of this thesis is the assessment of neighbourhood social capital we used. The assessment of neighbourhood social capital was derived from a nationally representative sample of residents from the Netherlands. The assessment of neighbourhood social capital was not based on the sample of individuals with chronic illness participating in the studies in this thesis. This enabled a clear distinction between individual social capital of people with chronic illness and neighbourhood social capital.

We used ecometric analysis to construct the social capital measure used in this thesis (Raudenbush et al., 1991; Raudenbush and Sampson, 1999; Raudenbush, 2003). The ecometric model partitions variance into three components: variation among neighbourhoods, variation among individuals, and variation within individuals among items used for the social capital measure. In our analysis we adjusted for differences between individuals within neighbourhoods by including a number of individual characteristics, such as sex, age, education, income, employment status, home ownership, and years of residence in the neighbourhood. This method allowed us to construct a measure of neighbourhood social capital purely based on contextual differences between neighbourhoods, whilst taking into account differences in social capital between neighbourhoods caused by selection effects. In the study of neighbourhood social

capital it is important to distinguish between compositional and contextual effects. Compositional effects would occur if the association between neighbourhood social capital and health would be caused by individual differences between residents in neighbourhoods (such as differences in age, individual social capital or socioeconomic status). For instance, people with chronic illness in a neighbourhood with more social capital might on average be younger and might therefore be in better health. To distinguish true contextual neighbourhood effects, we accounted for demographic and illness characteristics in the statistical models about the relationship between neighbourhood social capital and health of people with chronic illness. We found that neighbourhood social capital influenced changes in health of people with chronic illness, after accounting for individual factors. This finding shows that neighbourhood differences can not solely be attributed to differences between the people that live there. There is an independent 'place-effect' on health of people with chronic illness.

Causal relationship between neighbourhood social capital and health of people with chronic illness

As mentioned in the paragraph above, we found that neighbourhood social capital influenced changes in health of people with chronic illness. To date, the direction of the relationship between neighbourhood social capital and health has been unclear. The majority of previous studies investigating the relationship between neighbourhood social capital and health are cross-sectional. Recently, our findings were confirmed by another study. Ruijsbroek et al. (2016) found that improvements in neighbourhood social capital were associated with better health among the general population. In line with their study, the evidence presented in this thesis suggests that there is a causal relationship between neighbourhood social capital and health.

Suggestions for future research

Under what conditions can people with chronic illness benefit from neighbourhood social capital?

We found that neighbourhood social capital can benefit health of people with chronic illness, independent of individual social capital they possess. However, we found that support from neighbours is not a resource provided through neighbourhood social capital but is only accessible through individual connections to neighbours. Only those people with chronic illness that are personally connected to their neighbours will receive support from them. More research is necessary to gain insight into how living in a neighbourhood with more social capital can benefit people with chronic illness that are socially isolated and lack network connections to mobilize specific resources. The benefit of living in a neighbourhood with more social capital may be especially important for people with chronic illness, as they may have limited possibilities to build individual social capital. As mentioned previously in this chapter, people with chronic illness may be unable to go out and interact with their neighbours because they lack energy or have physical disabilities. They may also be busy with the tasks they are faced with in addition to the roles and responsibilities they fulfil in their daily life, such as exercising and regular medical appointments.

Next to the importance of individual social connections to mobilize neighbourhood resources, other individual characteristics – such as health literacy skills – may influence to which degree people with chronic illness can access and use neighbourhood resources. Others have also proposed that whether, how and to what degree the social environment is related to health can depend on many personal (such as age and gender) and environmental factors (Sharkey and Faber, 2014). The results of this thesis suggest that the effect of neighbourhood social capital on health depends on health literacy skills and on the physical disabilities people with chronic illness have. It is also possible that the effect of neighbourhood social capital depends on the support needs people with chronic illness have. Furthermore, as the results of this thesis suggest, it is possible that neighbourhood social capital only stimulates collective action in rural municipalities.

Future research should develop specific hypotheses about these possible heterogeneous effects of neighbourhood social capital on health of people with chronic illness.

What is the relevant neighbourhood scale for people with chronic illness?

In this thesis we defined neighbourhoods based on 4-digit postal codes. However, we do not know what the relevant neighbourhood size is for people with chronic illness. Literature based on neighbourhood effects which relies on the same area, namely postal codes in the Netherlands, presents evidence that suggests that neighbourhood social capital is related to individual health within the general population (Mohnen et al., 2011). However, it is possible that postal codes do not (always) reflect the boundaries of the neighbourhood as experienced by people with chronic illness. To gain insight into the benefit of neighbourhood social capital for health of people with chronic illness, it is necessary to identify the relevant neighbourhood scale by studying activity patterns of people with chronic illness. As mentioned previously, the relevant scale is also likely to be dependent on the mechanism under study. People with chronic illness might only get help from neighbours on their own street. However, they might have conversations with neighbours a few streets away and they might use services and amenities that are multiple blocks away.

Neighbourhood exposure of people with chronic illness: important for the effect of neighbourhood social capital on health?

The benefit of specific neighbourhood resources might not only depend on personal integration of people with chronic illness into specific networks (individual social capital), but might also depend on the exposure of people with chronic illness to a specific neighbourhood. Exposure refers to both the time people with chronic illness currently spend in their neighbourhood, as well as their residential history. It can be assumed that people with chronic illness who spend more time in their neighbourhood will more strongly experience the effects of neighbourhood social capital. The amount of time people with chronic illness spend in their neighbourhood, and their residential neighbourhood, may vary during the life course. For instance, people with chronic illness may have been differently exposed before their illness was diagnosed, and they might experience changes in the degree they are able to interact with neighbours as their illness progresses. In most Western countries, people spend a significant amount of their time outside their neighbourhood due to work or educational

demands. People with chronic illness may spend more time in their neighbourhood when their illness progresses because they less often have a paid job (Cozijnsen et al., 2016). With regard to evidence for the importance of exposure, Mohnen et al. found that the positive effect of neighbourhood social capital is only experienced after people live in the same neighbourhood for more than six years (Mohnen et al., 2013). Their results also show that living in a neighbourhood with more social capital is in particular beneficial for people with young children, whom they assumed to be more intensively exposed.

If they move between neighbourhoods, people with chronic illness might be exposed to different neighbourhoods with varying levels of social capital during their life. For instance, people with chronic illness might move from a neighbourhood with low social capital to a neighbourhood with high social capital, or the other way around. But, people with chronic illness might also only be exposed to either low social capital or high social capital neighbourhoods during the life course. Wheaton and Clarke (2003) report a correlation of .65 between neighbourhood SES in childhood and adulthood, suggesting that a large number of people are exposed to a specific type of neighbourhood during their life. This finding raises the issue of accounting for cumulative exposure to neighbourhood conditions, such as low or high neighbourhood social capital, as people age. They suggest that exposure to stressful conditions (e.g., crime, social disorder) in neighbourhoods can accumulate and reinforce the risk of poor health for people over time. It is possible that long term residence in a neighbourhood with low social capital reinforces the risk of poor health for people with chronic illness, because people with chronic illness continuously live in an environment where they lack the resources they need to improve health.

People with chronic illness may also choose to relocate as they grow older or when their health deteriorates. In the US, deterioration in health is associated with parents and children moving closer together (Silverstein, 1995). However, research in Sweden shows that when parents move closer to their children they are more likely to do this to help the younger generation (for instance with babysitting) than due to their own support needs (Pettersson and Malmberg, 2009). The authors relate this finding to the importance of public care institutions in the Swedish welfare state. Although we do not have any information on residential location of people with chronic illness due to their health condition, it is possible that people with chronic illness will be more

likely to move towards their children when it becomes more difficult to draw on professional care and support in the Netherlands. In the Netherlands people with health problems are increasingly urged to draw on support from their social network.

It is important to study the residential history of people with chronic illness to gain insight in the cumulative effect of neighbourhood exposure over time. To gain insight into cumulative neighbourhood exposure, it is also important to study the development of neighbourhoods, as the level of neighbourhood social capital may change substantially during the years (Sampson et al., 2002).

Recommendations for policy

The studies in this thesis have been conducted in light of developments in the Dutch policy of long-term care and support. The provision of support and home care for people with health problems and disabilities was reformed in 2007 by the introduction of the Social Support Act (Wmo). With the Social Support Act a greater part of the responsibility for the provision of support was delegated to the municipal level (Kroneman et al., 2016). In 2015 long-term care was reformed and the Social Support Act was extended. This means that municipalities have become even more responsible for the wellbeing of vulnerable groups and the fulfilment of their support needs. Coinciding with the decentralization of social support, there is increasing focus on individual responsibility of people with chronic illness for health and self-sufficiency. People with chronic illness are stimulated to utilize their social network and neighbourhood resources before appealing to municipal services. An important assumption is that people with chronic illness who need support indeed possess a social network and live in neighbourhoods that possess resources for health. However, people with chronic illness may be at risk of loneliness and social isolation. People with chronic illness are more often lonely than people without chronic illness (Penninx et al., 1999). This means that they may not have the social network and neighbourhood resources at their disposal to promote health and self-sufficiency.

To date there have been no community development programs focused on providing neighbourhood resources and support specifically for people with chronic illness. Community development programs focused on people with

chronic illness may stimulate people in a neighbourhood to cooperate to provide practical help, emotional support, activities and information which people with chronic illness may use to benefit health.

When the social support act was introduced in 2007 one of the goals was increasing social cohesion and liveability (in society in general and in neighbourhoods). In 2011, most local authorities linked this goal, among others, to stimulating informal caregiving and volunteering by providing support for volunteers and informal caregivers (Kromhout et al., 2014). The aim of these initiatives was to create 'caring neighbourhoods' and promoting social cohesion. However, there is no information on whether activities carried out to increase social cohesion and liveability actually increased neighbourhood social capital and increased access to resources for people with chronic illness.

Recently a new community approach has been developed: The Social Engagement Framework for Addressing the Chronic-disease-challenge (SEFAC). Four regional pilot projects have been set up, one of which is in the Netherlands. SEFAC aims to promote health and reduce the burden of chronic illness by encouraging people with chronic illness to co-create communities for the promotion of health, prevention and self-management. Community development programs such as this may be able to foster development of specific neighbourhood resources for people with chronic illness. How exactly people with chronic illness can benefit from community development programs is likely to depend on individual circumstances (Diez Roux and Mair, 2010; Sharkey et al., 2014). People with chronic illness have different skills, different goals and are faced with different challenges in everyday life. The relevance of neighbourhood resources therefore depends on the constraints and limitations people with chronic illness experience and the specific needs they have. Community development programs will thus require careful consideration of the specific group of people with chronic illness that is being targeted. There are a number of stakeholders that have an interest in efforts to increase neighbourhood resources for people with chronic illness. For instance, stakeholders that provide professional and informal support for people with chronic illness such as the municipality, healthcare professionals and the social network of people with chronic illness. Furthermore, there are a number of stakeholders that invest in maintaining and promoting social capital in neighbourhoods, for instance through neighbourhood initiatives such as community centres, social activities

and clubs, language programs or volunteer projects. These stakeholders should work together to develop an integrated view of how people with chronic illness can benefit from neighbourhood resources and how these resources can be promoted in neighbourhoods.

It is likely that some neighbourhood resources, among which is support by neighbours, will mainly be accessible through individual connections to neighbours. As mentioned previously, this means that people with chronic illness who are lonely and socially isolated may not be able to access the resources and support they need in their neighbourhood. People with chronic illness may therefore also benefit from individual interventions, support and training to enlarge their social network or intensify already existing social relationships. People with chronic illness can take part in interventions to increase their ability to form and maintain social bonds. Also, participation in social activities in the neighbourhood and introduction to existing neighbourhood networks and clubs, may help people with chronic illness to become more sociable and less lonely (Cattan et al., 2005; Cohen-Mansfield and Perach, 2015).

Conclusion

The main question this thesis aimed to answer was: “Is neighbourhood social capital related to health of people with chronic illness? And if so, how can we explain the relationship between neighbourhood social capital and health of people with chronic illness?”.

The studies in this thesis have shown that neighbourhood social capital is indeed related to (changes in) health of people with chronic illness. This thesis supports the assumption that connections between neighbours can contribute to the possibilities people with chronic illness have to maintain and improve their health in light of the health challenges they face every single day. The qualitative study of this thesis also showed that people with chronic illness experience that neighbours provide valuable forms of support for health and self-management. However, we did not find evidence that people with chronic illness can access support by neighbours simply through living in a neighbourhood with more social capital. This means that people with chronic illness who are lonely and socially isolated may not be able to access the support they need in their neighbourhood.

Based on the results of this thesis we cannot draw conclusions on how neighbourhood social capital benefits health of people with chronic illness. There is no evidence that neighbourhood social capital provides a number of specific resources for the group of people with chronic illness as a whole. As mentioned above, this thesis does provide evidence for heterogeneous effects of neighbourhood social capital on health based on health literacy skills, physical disabilities and urbanity of the neighbourhood. Based on the results of this thesis there is no indication that resources provided through neighbourhood social capital can compensate or substitute other types of resources or support provided by healthcare professionals, the municipality or the social network. The results of this study urge healthcare professionals as well as policy makers to not overestimate the resources the neighbourhood can provide for people with chronic illness who are socially isolated and lack the skills to gain access to resources. The neighbourhood cannot be viewed as a 'one size fits all' - solution to the care needs of people with chronic illness. As mentioned previously, more research is needed to draw conclusions on how the neighbourhood can contribute to health of people with chronic illness.

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Samenvatting

Introductie

Is het sociaal kapitaal in de buurt van invloed op de gezondheid van mensen met een chronische ziekte? En zo ja, op wat voor wijze? Dat was de vraag die in dit proefschrift centraal stond. Eerder onderzoek heeft uitgewezen dat de buurtomgeving invloed kan hebben op individueel welzijn en levenskansen. Eén van de manieren waarop de buurt van invloed kan zijn, is door de sociale contacten die er tussen buurtgenoten bestaan. Door de contacten die er zijn tussen buurtgenoten worden hulpbronnen gegenereerd. Deze hulpbronnen kunnen worden aangeduid als 'sociaal kapitaal'. Het kenmerkende van buurt sociaal kapitaal is dat dit, in tegenstelling tot individueel sociaal kapitaal, een buurtkenmerk is en geen eigenschap van de relaties tussen specifieke individuen. Dat betekent dat de hulpbronnen die er zijn in buurten met meer sociaal kapitaal, ook gebruikt kunnen worden door mensen die zelf geen nauwe contacten onderhouden met anderen in hun buurt. Eerder onderzoek heeft uitgewezen dat buurt sociaal kapitaal gerelateerd is aan individuele gezondheid. Het is echter onduidelijk of een goede gezondheid leidt tot meer sociaal kapitaal, of dat sociaal kapitaal leidt tot een betere gezondheid. Het is immers ook mogelijk dat buurtbewoners die gezonder zijn meer mogelijkheden hebben om te investeren in de sociale contacten met anderen. Het is ook onduidelijk op wat voor wijze buurt sociaal kapitaal van invloed kan zijn op individuele gezondheid. Het doel van de studies in dit proefschrift is om meer inzicht te krijgen in het effect van buurt sociaal kapitaal op de gezondheid van mensen met een chronische ziekte. Mensen met een chronische ziekte hebben te maken met verschillende taken als gevolg van hun ziekte, waaronder het omgaan met de symptomen en lichamelijke gevolgen van hun ziekte, de behandeling van hun ziekte, het maken van leefstijlaanpassingen, en het omgaan met de psychische en sociale gevolgen van hun ziekte (CBO, 2001). Mensen met een chronische ziekte kunnen de hulpbronnen in hun buurt mogelijk gebruiken om met de gevolgen van hun ziekte in het dagelijks leven om te gaan.

De hoofdvraag van dit proefschrift is:

“Is er een relatie tussen buurt sociaal kapitaal en de gezondheid van mensen met een chronische ziekte? En zo ja, hoe kunnen we de relatie tussen buurt sociaal kapitaal en de gezondheid van mensen met een chronische ziekte verklaren?”

Het meten van buurt sociaal kapitaal

In dit proefschrift wordt de buurt gedefinieerd op basis van 4-cijferige postcode gebieden. Om het sociaal kapitaal in de buurt te meten maken wij gebruik van datasets die representatief zijn voor de volwassen Nederlandse bevolking. Deze datasets zijn gebaseerd op data van het WoonOnderzoek Nederland (WoOn). Voor dit onderzoek zijn aan Nederlandse volwassenen vragen gesteld over de contacten die zij hebben met anderen in hun buurt en hoe mensen in de buurt met elkaar omgaan. Op basis van deze vragen hebben wij per buurt de hoeveelheid sociaal kapitaal vastgesteld. Om gegevens over de gezondheid van mensen met een chronische ziekte te verkrijgen, hebben wij gebruik gemaakt van gegevens uit vragenlijsten die ingevuld zijn door leden van het Nationaal Panel Chronisch zieken en Gehandicapten (NPCG). Dit panel bevat door de jaren heen circa 3,500-4000 leden met een chronische ziekte of lichamelijke beperking. Buurt sociaal kapitaal is dus niet gemeten onder de groep mensen met een chronische ziekte die in dit proefschrift centraal staat. Dat wil zeggen dat de hoeveelheid sociaal kapitaal in buurten onafhankelijk van de gegevens van mensen met een chronische ziekte is vastgesteld.

Samenvatting van resultaten

Buurt sociaal kapitaal heeft een positief effect op gezondheidsveranderingen van mensen met een chronische ziekte

In de eerste studie van dit proefschrift hebben wij gekeken naar het effect van zowel buurt sociaal kapitaal als individueel sociaal kapitaal op veranderingen in de gezondheid van mensen met een chronische ziekte. Door te kijken naar veranderingen in gezondheid is het mogelijk om evidentie te vinden voor een causale relatie tussen buurt sociaal kapitaal en gezondheid. Wanneer buurt sociaal kapitaal op één moment gemeten is, en in daaropvolgende jaren gekeken wordt naar veranderingen in gezondheid, kan uitgesloten worden dat gezondheid van invloed is op de eerder gemeten hoeveelheid buurt sociaal kapitaal. De resultaten van dit onderzoek laten zien dat zowel buurt sociaal kapitaal als individueel sociaal kapitaal van invloed zijn op veranderingen in de gezondheid van mensen met een chronische ziekte. Dat er een onafhankelijk effect is van buurt sociaal kapitaal betekent dat buurt sociaal kapitaal ook bij kan dragen aan de gezondheid van mensen met een chronische ziekte die individueel sociaal kapitaal missen. Ook mensen met een chronische ziekte die nauwelijks

contact hebben met hun buren kunnen dus profiteren van het wonen in een buurt met veel sociaal kapitaal. Dit is relevant voor mensen met een chronische ziekte omdat zij ten gevolge van hun ziekte mogelijk minder in staat zijn om te investeren in sociale contacten met hun buren. Zo kunnen zij een gebrek hebben aan fysieke of mentale energie en kunnen zij te maken hebben met lichamelijke beperkingen waardoor zij niet zo makkelijk de deur uit gaan. De volgende studies in dit proefschrift waren er op gericht om meer inzicht te krijgen in de wijze waarop buurt sociaal kapitaal bij kan dragen aan de gezondheid van mensen met een chronische ziekte.

Buren leveren waardevolle maar beperkte bijdragen aan de gezondheid en het zelfmanagement van mensen met een chronische ziekte

Om meer inzicht te krijgen in de mening van mensen met een chronische ziekte over de manier waarop buren, en andere leden van het sociale netwerk, bijdragen aan gezondheid en zelfmanagement hebben wij een kwalitatieve studie uitgevoerd. De resultaten van deze studie laten zien dat buren met name praktisch bijdragen aan het zelfmanagement van mensen met een chronische ziekte. Zo doen zij klusjes in en om het huis, doen zij werk in de tuin en helpen zij bijvoorbeeld praktisch met boodschappen tillen. Deze vormen van hulp zijn belangrijk omdat zij er aan bijdragen dat mensen met een chronische ziekte zelfstandig kunnen blijven wonen, ondanks dat zij bepaalde dingen zelf niet meer of minder makkelijk kunnen. Een belangrijk kenmerk van de relatie met buurtgenoten is dat zij altijd dichtbij zijn en dus ook kunnen helpen als er snel iets gedaan moet worden of als er onverwacht iets gebeurt (e.g. er moet een lamp vervangen worden die kapot gaat). Mensen met een chronische ziekte geven echter wel aan dat zij niet teveel hulp van hun buren willen vragen of accepteren. En ook het type hulp is van belang. Zo helpen buren maar zelden bij medische taken of bij persoonlijke verzorging. Hierin verschillen de relaties met buren van de relaties met vrienden. Vrienden kiest men immers ook zelf, terwijl dit bij buren over het algemeen niet het geval is. Vrienden zijn dan ook vaker dan buren een bron van emotionele steun. Deze resultaten laten zien dat er, vanuit het perspectief van mensen met een chronische ziekte zelf, grenzen zitten aan de hulp die men van hun buren kan of wil krijgen.

Buurt sociaal kapitaal is niet gerelateerd aan de beschikbaarheid van Wmo-voorzieningen

Mensen met een chronische ziekte kunnen profiteren van toegang tot Wmo-voorzieningen. Wmo-voorzieningen zijn er op gericht om zelfredzaamheid en participatie te bevorderen. Wij stelden dat buurt sociaal kapitaal de toegang tot deze voorzieningen mogelijk kan vergroten, doordat mensen in buurten met meer sociaal kapitaal meer geneigd zijn om gezamenlijke actie te ondernemen voor een gemeenschappelijk doel. In buurten met meer sociaal kapitaal komen bewoners dan wellicht ook vaker in actie voor betere toegang tot voorzieningen in hun buurt. Wij onderzochten de relatie tussen buurt sociaal kapitaal, de motivatie van buurtgenoten om gezamenlijk actie te ondernemen, en drie typen Wmo-voorzieningen. Dit waren: Wmo-voorzieningen die er op gericht zijn om mantelzorgers te ondersteunen; individuele voorzieningen zoals huishoudelijke hulp, woningaanpassingen en maaltijdvoorzieningen; en algemene en collectieve voorzieningen zoals een uitleenpunt voor rolstoelen, vervoersvoorzieningen en sportfaciliteiten. De resultaten van deze studie laten zien dat buurt sociaal kapitaal, alsmede de bereidheid van buurtgenoten om gezamenlijk actie te ondernemen voor een gemeenschappelijk doel, gerelateerd waren aan de aanwezigheid van voorzieningen ter ondersteuning van mantelzorgers in plattelandsgemeenten. Dit impliceert dat sociaal kapitaal in plattelandsgemeenten er aan kan bijdragen dat buurtbewoners gezamenlijk actie ondernemen om de toegang tot voorzieningen te verbeteren. Echter is het bewijs hiervoor niet eenduidig, omdat wij geen andere verbanden vonden tussen buurt sociaal kapitaal en de aanwezigheid van Wmo-voorzieningen.

Mensen met een chronische ziekte ontvangen niet vaker praktische hulp of emotionele steun van burens in buurten met meer sociaal kapitaal

In de vierde studie van dit proefschrift onderzochten we of mensen met een chronische ziekte vaker praktische hulp of emotionele steun ontvangen van hun buurtgenoten als zij in een buurt wonen met meer sociaal kapitaal. We veronderstelden dat mensen in een buurt met meer sociaal kapitaal meer geneigd zijn om hun burens te helpen, zelfs als ze deze niet persoonlijk goed kennen. Wanneer iemand lang niet buiten geweest is kunnen buurtgenoten informeren of er hulp nodig is. Ook kunnen zij een praatje met andere maken op straat, even helpen in de tuin of bijvoorbeeld zware boodschappen voor iemand dragen. Echter vonden we geen bewijs voor de hypothese dat mensen met een chronische ziekte vaker hulp van hun burens krijgen als zij in een buurt wonen

met meer sociaal kapitaal. Mensen met een chronische ziekte krijgen slechts vaker hulp van hun burens als zij zelf meer connecties met hun burens hebben. Deze bevinding wordt bevestigd door eerder onderzoek (Carpiano, 2006; Carpiano, 2008) dat liet zien dat alleen degenen die onderdeel uitmaken van een specifiek netwerk toegang hebben tot bepaalde hulpbronnen. Sommige hulpbronnen in de buurt, zoals een gevoel van veiligheid door meer sociale controle (Sampson et al., 1997), kunnen van nut zijn voor alle bewoners, ook als mensen zelf geen persoonlijke connecties met hun burens hebben. Echter zijn er geen aanwijzingen dat dit geldt voor alle andere hulpbronnen in een buurt, zoals praktische hulp of emotionele ondersteuning.

Buurt sociaal kapitaal heeft een positief effect op het zelfmanagement van mensen met een chronische ziekte en lichte lichamelijke beperkingen

In de vijfde studie van dit proefschrift onderzochten we of buurt sociaal een positief effect heeft op het zelfmanagement van mensen met een chronische ziekte. Zelfmanagement is een multidimensionaal concept en omvat zowel medische taken als taken gerelateerd aan het omgaan met de fysieke, emotionele en sociale gevolgen van de aandoening in het dagelijks leven. Ook leefstijlaanpassingen kunnen onderdeel zijn van zelfmanagement. Het is niet waarschijnlijk dat de hulpbronnen in de buurt bijdragen aan alle onderdelen van zelfmanagement. Wij veronderstelden dat de hulpbronnen in de buurt met name ten goede komen aan de niet-medische aspecten van zelfmanagement, zoals het maken van leefstijlaanpassingen en het omgaan met de fysieke, sociale en emotionele gevolgen van de aandoening. Wij vonden alleen een relatie tussen het sociaal kapitaal in de buurt en het zelfmanagement van mensen met een chronische ziekte met lichte lichamelijke beperkingen. Buurt sociaal kapitaal had geen effect op het zelfmanagement van mensen met een chronische ziekte zonder lichamelijke beperkingen of mensen met een chronische ziekte met matige of ernstige lichamelijke beperkingen. Mensen met een chronische ziekte die in het geheel geen lichamelijke beperkingen ervaren hebben mogelijk geen hulpbronnen in de buurt nodig om zelfmanagement te verrichten. Wanneer mensen met een chronische ziekte echter matige of ernstige lichamelijke beperkingen hebben, kunnen zij in de buurt wellicht niet de hulpbronnen vinden die zij nodig hebben om met de gevolgen van hun beperkingen voor zelfmanagement om te gaan. Het is bijvoorbeeld mogelijk dat mensen met een chronische ziekte met lichte lichamelijke beperkingen baat hebben bij meer toegang tot gezondheidsinformatie over sportvoorzieningen, terwijl mensen met

een chronische ziekte met matige of ernstige lichamelijke beperkingen geen baat hebben bij generieke sport- en leefstijladviezen. Zij hebben mogelijk behoefte aan hulpbronnen die meer toegepast zijn op hun situatie en afgestemd zijn op hun ondersteuningsbehoefte.

Geen aanwijzingen dat meer toegang tot gezondheidsinformatie in buurten met meer sociaal kapitaal kan compenseren voor beperkte gezondheidsvaardigheden van mensen met een chronische ziekte

Mensen met een chronische ziekte moeten toegang verkrijgen tot gezondheidsinformatie en deze begrijpen en toepassen om beslissingen te maken over hun gezondheid. Bijvoorbeeld over de symptomen die zij ervaren, de zorg die zij nodig hebben, medicijnen of leefstijlveranderingen. Wij veronderstelden dat buurt sociaal kapitaal van invloed kan zijn op gezondheid omdat het de toegang tot gezondheidsinformatie vergroot (Kawachi et al., 1999; Kawachi et al., 2007). Mensen met een chronische ziekte kunnen van hun buurtgenoten wellicht informatie krijgen over plekken om gezond eten te kopen, sportverenigingen in de buurt, of een goede fysiotherapeut die zich in de buurt heeft gevestigd. Wij onderzochten of buurt sociaal kapitaal met name bevorderlijk is voor de gezondheid van mensen met een chronische ziekte met lage gezondheidsvaardigheden. Gezondheidsvaardigheden zijn de vaardigheden van mensen om informatie over gezondheid te verkrijgen, te begrijpen, te beoordelen en te gebruiken bij het nemen van gezondheids-gerelateerde beslissingen (Beauchamp et al., 2015; Begoray and Kwan, 2012). Mensen met een chronische ziekte met lage gezondheidsvaardigheden kunnen problemen hebben met het vinden en begrijpen van gezondheidsinformatie en het vinden van de zorg en voorzieningen die zij nodig hebben. Wij veronderstelden dat juist mensen met een chronische ziekte met lage gezondheidsvaardigheden dan ook kunnen profiteren van toegang tot gezondheidsinformatie in hun buurt. Echter, wij stelden ook dat het mogelijk is dat mensen met een chronische ziekte gezondheidsvaardigheden nodig hebben om toegang te krijgen tot hulpbronnen in de buurt. Mogelijk missen mensen met een chronische ziekte met lage gezondheidsvaardigheden de kennis en vaardigheden die zij nodig hebben om hulpbronnen in de buurt te gebruiken. De resultaten van deze studie lieten zien dat buurt sociaal kapitaal niet kan compenseren voor lage gezondheidsvaardigheden. Buurt sociaal kapitaal heeft met name een positief effect op de gezondheid van mensen met een chronische ziekte die beter in staat zijn om gezondheidsinformatie te vinden en te begrijpen. Deze resultaten

impliceren dat verschillen in gezondheidsvaardigheden kunnen zorgen voor ongelijkheid tussen mensen met een chronische ziekte in de mate waarin zij toegang hebben tot hulpbronnen in de buurt.

Reflectie op de resultaten

De resultaten van dit proefschrift laten zien dat het effect van buurt sociaal kapitaal op gezondheid niet hetzelfde is voor verschillende subgroepen van mensen met een chronische ziekte. Wij vonden verschillen in het effect van buurt sociaal kapitaal op basis van de lichamelijke beperkingen die mensen met een chronische ziekte hebben, op basis van verschillen in gezondheidsvaardigheden, en op basis van de stedelijkheid van de buurt waarin mensen wonen. Het is mogelijk dat wij geen verder bewijs vonden voor de veronderstelde mechanismen achter de relatie tussen buurt sociaal kapitaal en gezondheid omdat wij onvoldoende rekening hebben gehouden met de diversiteit van de groep mensen met een chronische ziekte. Er kunnen grote verschillen zijn tussen mensen met een chronische ziekte en de gevolgen die zij ondervinden van hun ziekte. Mensen met een chronische ziekte kunnen verschillen in de mate waarin zij behoefte hebben aan hulpbronnen in de buurt, maar ook in de individuele mogelijkheden die zij hebben om buurt sociaal kapitaal te benutten. Wij hebben in dit proefschrift rekening gehouden met verschillen in demografische en ziekte- kenmerken tussen mensen met een chronische ziekte. Het kan echter nodig zijn om rekening te houden met aanvullende verschillen tussen mensen met een chronische ziekte die voorspellend zijn voor het effect van buurt sociaal kapitaal op gezondheid. Daarbij kan bijvoorbeeld gedacht worden aan individuele kenmerken zoals gezondheidsvaardigheden, de ervaren ondersteuningsbehoefte, de motivatie om zorg te dragen voor de gezondheid, of het vertrouwen dat men heeft in de eigen vaardigheden om beslissingen te maken over gezondheid.

In de studies in dit proefschrift hebben wij een aantal andere buurtkenmerken meegenomen, waaronder de stedelijkheid van de gemeente waarin een buurt zich bevindt en de sociaaleconomische status van een buurt. Het is echter mogelijk dat wij andere fysieke en sociale kenmerken van een buurt hadden moeten includeren in onze studies om meer bewijs te vinden voor de veronderstelde mechanismen achter de relatie tussen buurt sociaal kapitaal en

gezondheid. Het is mogelijk dat mensen met een chronische ziekten in sommige buurten meer baat hebben bij buurt sociaal kapitaal dan in andere buurten. Als mensen met een chronische ziekte bijvoorbeeld in een buurt wonen met een park, kunnen zij dat park gebruiken om te wandelen. Echter, als zij geen park of prettige wandelplek in de buurt hebben moeten zij wellicht eerder aan hun buren vragen om hen een lift te geven naar een park dat verder weg is. Een ander mogelijk voorbeeld is dat mensen met een chronische ziekte met een visuele beperking niet goed alleen 's avonds over straat kunnen in een buurt die slecht verlicht is. Zij moeten hun buurtgenoten dan mogelijk vragen om hen te vergezellen als zij over straat moeten. In een buurt die goed verlicht is, kunnen zij wellicht makkelijker zelfstandig de deur uit. Ook hebben mensen met een chronische ziekte mogelijk minder behoefte aan hulpbronnen gegeneerd door buurt sociaal kapitaal als er goede voorzieningen in hun buurt zijn. Het niet includeren van andere relevante buurtkenmerken kan leiden tot het overschatten of onderschatten van het effect van buurt sociaal kapitaal op de gezondheid van mensen met een chronische ziekte.

Mogelijk hadden wij ook meer bewijs gevonden voor de veronderstelde mechanismen achter de relatie tussen buurt sociaal kapitaal en gezondheid als wij meer informatie hadden over het gebruik van hulpbronnen in de buurt door mensen met een chronische ziekte. Wij hadden slechts informatie over de praktische hulp en emotionele steun die mensen met een chronische ziekte ontvangen van hun buurtgenoten. We hadden geen informatie over het gebruik van Wmo-voorzieningen, over de manier waarop mensen met een chronische ziekte gezondheidsinformatie in buurten gebruiken, of over de manier waarop mensen met een chronische ziekte hulpbronnen in de buurt gebruiken ten bate van zelfmanagement. Daarnaast is het mogelijk dat er nog andere manieren zijn waarop buurt sociaal kapitaal de gezondheid van mensen met een chronische ziekte beïnvloedt die wij niet onderzocht hebben. Zo kan buurt sociaal kapitaal ook effect hebben op het emotionele welbevinden van mensen met een chronische ziekte doordat zij zich prettiger voelen in buurten waar bewoners op vriendelijke wijze met elkaar omgaan. Het is ook mogelijk dat buurt sociaal kapitaal niet met name van invloed is op de gezondheid van mensen met een chronische ziekte doordat zij gebruik maken van specifieke hulpbronnen, maar doordat zij ervaren dat er hulpbronnen beschikbaar zijn wanneer zij deze eventueel nodig hebben.

Wij hebben een algemene maat van buurt sociaal kapitaal gebruikt, gebaseerd op informatie over contacten tussen buurtgenoten. Het is mogelijk dat wij meer bewijs voor de veronderstelde mechanismen achter de relatie tussen buurt sociaal kapitaal en de gezondheid van mensen met een chronische ziekte hadden gevonden als wij een specifiekere meting van buurt sociaal kapitaal gebruikt hadden. Coleman (1988) zegt dat sociaal kapitaal gedefinieerd wordt door de functie die het heeft. De verschillende hulpbronnen die gegenereerd worden in de relaties tussen buurtgenoten zijn niet automatisch uitwisselbaar. Specifieke hulpbronnen kunnen nuttig zijn om het ene doel te vervullen, maar kunnen in een andere situatie helemaal geen functie hebben. Dat betekent dat sommige buurten met sociaal kapitaal veel hulpbronnen kunnen hebben die mensen met een chronische ziekte kunnen gebruiken ten bate van hun gezondheid (e.g. meer toegang tot gezondheidsinformatie), maar dat andere buurten hulpbronnen kunnen hebben die niet bijdragen aan de gezondheid van mensen met een chronische ziekte (e.g. door burens georganiseerde activiteiten voor kinderen).

Het is ook mogelijk dat de schaal van de buurt zoals wij die gemeten hebben niet de juiste was om bewijs te vinden voor de veronderstelde mechanismen achter de relatie tussen buurt sociaal kapitaal en gezondheid van mensen met een chronische ziekte. We hebben gebruik gemaakt van 4-cijferige postcodegebieden om de buurt te meten. Echter is het mogelijk dat de omvang van deze gebieden juist te groot of te klein was voor de mechanismen die wij onderzochten. Het is waarschijnlijk dat de passende operationalisatie van de buurt afhankelijk is van het mechanisme dat onderzocht wordt. Dat betekent dat voor elke studie in dit proefschrift mogelijk een andere operationalisatie van de buurt passend geweest zou zijn. Wanneer we kijken naar de ondersteuning die mensen met een chronische ziekte van hun buurtgenoten ontvangen, is het mogelijk dat de relevante buurtomgeving relatief klein is. Mensen met een chronische ziekte ontvangen mogelijk slechts ondersteuning van mensen uit dezelfde straat. Wanneer we kijken naar toegang tot gezondheidsinformatie is het mogelijk dat de relevante schaal groter is, omdat mensen met een chronische ziekte ook in gesprek kunnen gaan met mensen die een paar straten verder wonen. Het is belangrijk dat de geografische schaal passend is voor het mechanisme dat bestudeerd wordt. Wij hadden geen toegang tot data om buurten op kleinere schaal te meten dan dat wij nu gedaan hebben.

Suggesties voor toekomstig onderzoek

Toekomstig onderzoek kan uitwijzen onder welke voorwaarden mensen met een chronische ziekte kunnen profiteren van buurt sociaal kapitaal. Daarbij kan verder voortgebouwd worden op onze bevindingen dat het effect van buurt sociaal kapitaal op de gezondheid van mensen met een chronische ziekte afhankelijk is van de mate van lichamelijke beperkingen en van gezondheidsvaardigheden. Meer onderzoek is ook nodig om aan te tonen hoe mensen met een chronische ziekte die sociaal geïsoleerd zijn en sociale contacten in hun buurt missen, kunnen profiteren van de hulpbronnen die gegenereerd worden in buurten. Daarnaast is het van belang om te onderzoeken wat de relevante grootte is van de buurtomgeving voor mensen met een chronische ziekte. Welke straal rondom hun huis zien zij als de buurt? En hoe verschilt de grootte van de buurt op basis van het onderzochte mechanisme achter de relatie tussen buurt sociaal kapitaal en gezondheid?

Het is ook mogelijk dat de het effect van buurt sociaal kapitaal op de gezondheid van mensen met een chronische ziekte afhankelijk is van de mate waarin mensen 'blootgesteld' worden aan hun buurt. Het is mogelijk belangrijk hoe lang mensen met een chronische ziekte reeds in hun buurt wonen, en hoeveel tijd zij daar doorbrengen. Het is ook mogelijk dat de hoeveelheid tijd die mensen met een chronische ziekte in hun buurt door brengen door de jaren heen varieert. Zo kunnen mensen met een chronische ziekte juist veel meer of minder tijd in hun buurt doorbrengen na de diagnose van hun ziekte. Mensen met een chronische ziekte kunnen bijvoorbeeld meer tijd in hun buurt gaan doorbrengen als gevolg van hun ziekte omdat zij geen betaald werk kunnen verrichten. Mensen met een chronische ziekte hebben minder vaak een betaalde baan dan de algemene bevolking (Cozijnsen et al., 2016). Als mensen met een chronische ziekte hun hele leven in een buurt met weinig sociaal kapitaal wonen, ervaren zij mogelijk sterker de nadelige effecten van laag buurt sociaal kapitaal op hun gezondheid dan mensen die slechts een kortere periode in een buurt wonen met laag sociaal kapitaal. Longitudinaal onderzoek naar de woongeschiedenis van mensen met een chronische ziekte kan hier duidelijkheid over scheppen. Longitudinaal onderzoek moet ook rekening houden met ontwikkelingen in buurten. Het sociaal kapitaal in een buurt kan aanzienlijk veranderen door de jaren heen (Sampson et al., 2002).

Aanbevelingen voor beleid

De studies in dit proefschrift zijn uitgevoerd in het licht van de veranderingen in de langdurige zorg die de afgelopen jaren hebben plaatsgevonden. Gemeenten zijn door de invoering van de Wmo in 2007, en de hervormingen van de langdurige zorg in 2015, in toenemende mate verantwoordelijk geworden voor de ondersteuning van mensen met gezondheidsproblemen. Er is ook in toenemende mate een focus op de individuele verantwoordelijkheid van mensen met een chronische ziekte voor hun gezondheid en zorg. Mensen met een chronische ziekte worden aangemoedigd om gebruik te maken van informele zorg en van hulpbronnen in de buurt, voor zij een beroep doen op professionele zorg en ondersteuning. Echter heeft niet iedereen met een chronische ziekte een sociale omgeving die kan bijdragen aan hun gezondheid. Buurtinitiatieven kunnen mogelijk bijdragen aan de ontwikkeling van gezondheidsbevorderende buurten voor mensen met een chronische ziekte. Er zijn tot op heden geen buurtinitiatieven bekend specifiek voor mensen met een chronische ziekte. Buurtinitiatieven gericht op mensen met een chronische ziekte kunnen buurtgenoten mogelijk bewegen om door samenwerking praktische hulp, emotionele ondersteuning, activiteiten en gezondheidsinformatie voor mensen met een chronische ziekte te realiseren. In de Wmo 2007 was het bevorderen van de sociale samenhang en leefbaarheid één van de prestatievelden. In het kader van dit doel richtten gemeenten zich het meest nadrukkelijk op het bevorderen van mantelzorg en vrijwilligerswerk door het verstrekken van ondersteuning voor mantelzorgers en vrijwilligers (Kromhout et al., 2014). Echter is niet bekend in hoeverre inspanningen van gemeenten in dit kader ook daadwerkelijk bijgedragen hebben aan de sociale cohesie en leefbaarheid in buurten. Recent is een nieuw buurtinitiatief ontwikkeld: Het 'Social Engagement Framework for Addressing the Chronic-disease-challenge (SEFAC)'. Voor dit initiatief zijn vier regionale pilots opgezet, waarvan één in Nederland. Het doel van SEFAC is om gezondheid te bevorderen en de lasten van chronische aandoeningen te verminderen door programma's gericht op de buurt. Mensen met een chronische ziekte moeten zelf als vrijwilligers en stakeholders actief worden in hun eigen buurt en gezonde leefgewoonten promoten. Op deze manier worden mensen met chronische ziekte ook aangemoedigd om zelf betrokken te zijn bij de creatie van gezondheidsbevorderende buurten. Op wat voor wijze mensen met een chronische ziekte baat hebben bij programma's zoals SEFAC is mogelijk afhankelijk van hun persoonlijke situatie (Diez Roux and

Mair, 2010; Sharkey et al., 2014). Mensen met een chronische ziekte verschillen in de vaardigheden, doelen en uitdagingen of problemen die zij hebben als gevolg van hun ziekte. Mensen met een chronische ziekte kunnen dan ook sterk verschillen in de hulpbronnen die zij nodig hebben om hun doelen te behalen. Buurtinitiatieven vereisen dan ook afstemming op de lokale gemeenschap. Niet alleen kunnen buurtinitiatieven mogelijk bijdragen aan de gezondheid van mensen met een chronische ziekte. Ook het vergroten van de mogelijkheden die mensen met een chronische ziekte hebben om persoonlijke relaties op te bouwen en te verdiepen is belangrijk. Mensen met een chronische ziekte lopen een hoger risico op eenzaamheid dan de algemene bevolking en zijn daardoor mogelijk extra kwetsbaar (Penninx et al., 1999). Zoals eerder genoemd in dit hoofdstuk is het waarschijnlijk dat sommige hulpbronnen in de buurt ook alleen toegankelijk zijn door persoonlijke relaties met buurtgenoten. Mensen met een chronische ziekte kunnen dan ook baat hebben bij interventies of trainingen die er op gericht zijn om hun sociale netwerk in de buurt te versterken. Ook participatie in sociale activiteiten of clubs in de buurt kan mensen met een chronische ziekte helpen om hun sociale netwerk te vergroten en eenzaamheid te verminderen (Cattan et al., 2005; Cohen-Mansfield and Perach, 2015).

Conclusie

De hoofdvraag van dit proefschrift was: 'Is buurt sociaal kapitaal gerelateerd aan de gezondheid van mensen met een chronische ziekte? En zo ja, hoe kunnen we de relatie tussen buurt sociaal kapitaal en de gezondheid van mensen met een chronische ziekte verklaren?'

De onderzoeken in dit proefschrift hebben laten zien dat buurt sociaal kapitaal gerelateerd is aan veranderingen in gezondheid van mensen met een chronische ziekte. Daarmee bevestigt dit proefschrift de hypothese dat buurt sociaal kapitaal kan bijdragen aan de mogelijkheden die mensen met een chronische ziekte hebben om hun gezondheid te bevorderen in het licht van de uitdagingen waar ze door hun chronische ziekte mee te maken hebben. De kwalitatieve studie in dit proefschrift liet ook zien dat mensen met een chronische ziekte ervaren dat buurtgenoten belangrijke vormen van praktische hulp en emotionele steun verstrekken. Echter vonden we geen bewijs dat mensen met een chronische ziekte toegang hebben tot deze ondersteuning wanneer zij wonen in een buurt

met meer sociaal kapitaal. Alleen door persoonlijke relaties tussen burens hebben mensen toegang tot ondersteuning.

Op basis van de resultaten van dit proefschrift kunnen wij geen conclusies trekken over de manier waarop buurt sociaal kapitaal de gezondheid van mensen met een chronische ziekte beïnvloedt. Wel laten de resultaten van dit proefschrift zien dat het effect van buurt sociaal kapitaal op de gezondheid van mensen met een chronische ziekte niet eenduidig is en afhankelijk van verschillende individuele kenmerken en van de stedelijkheid van de buurt waarin mensen wonen. Op basis van dit proefschrift is er geen aanleiding om te zeggen dat hulpbronnen in de buurt kunnen compenseren voor andere hulpbronnen of vormen van ondersteuning die mensen ontvangen van professionele zorgverleners, de gemeente of het sociale netwerk. Met name voor mensen met een chronische ziekte die geen sociale contacten in hun buurt hebben en die specifieke vaardigheden missen, kan het moeilijk zijn om toegang te krijgen tot hulpbronnen in de buurt. De buurt kan dan ook niet als pasklare oplossing ingezet worden om in de ondersteuningsbehoeften van mensen met een chronische ziekte te voorzien. Meer onderzoek is nodig om verdere conclusies te kunnen trekken over hoe de buurt bij kan dragen aan de gezondheid van mensen met een chronische ziekte.

Dankwoord

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Curriculum Vitae

Geeke Waverijn was born on the 27th of July 1990 in Tiel, The Netherlands. She obtained a Liberal Arts and Sciences degree from University College Roosevelt in Middelburg.

In 2012 she obtained her Master's degree in sociology from the VU University in Amsterdam.

In 2012 she started working at NIVEL, the Netherlands Institute for Health Services Research. She worked on projects within the research program 'Care demand of chronically ill and disabled'. The projects were, among others, focused on determinants of health and self-management, use of professional healthcare, receipt of informal care, and experienced quality of care by people with chronic illness.

For these projects, data was collected among members of the National Panel of people with a Chronic illness or physical Disability.

In 2013, she started with the research described in this PhD thesis, under the supervision of prof. dr. Peter Groenewegen and dr. Monique Heijmans. Currently, she is working at Maastricht hospital as a Business Intelligence Developer.