Chronic conditions and informal social capital

Mediators and moderators in different contexts

Elize Vis

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Colofon
Chronic conditions and informal social capital: Mediators and moderators in different contexts

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Mediators and moderators in different contexts

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CHAPTER 1

Synthesis

1.1 Context and relevance of this study

Growing attention for the societal participation and social networks of people with chronic and disabling conditions

Chronic conditions are an increasing challenge for healthcare systems in Europe, including the Netherlands. Not only is the number of people with one chronic condition rising, but so is the number of people with more than one chronic condition (National Institute of Public Health and the Environment, 2022). In the Netherlands in 2018, around 60% of the population had one or more chronic conditions and one third of the Dutch population had two or more chronic conditions (National Institute of Public Health and the Environment, 2022). Also, one in eight people in the Netherlands had a physical limitation regarding movement, seeing or hearing (National Institute of Public Health and the Environment, 2020). People of all ages can develop a chronic condition, but 96% of people older than 75 in the Netherlands have a chronic condition (National Institute of Public Health and the Environment, 2022). So, one of the causes of the challenges that healthcare systems face regarding the increase of chronic conditions is the rapid increase of life expectancy[1] (Eurostat, 2022). These developments pose new challenges for healthcare systems.

As a result, societal participation of anyone with a chronic or disabling condition is a topic that gained attention. For example, in 2008 the Convention of the Rights of Persons with Disabilities took effect (United Nations, 2008). It was ratified by the Netherlands in 2016, following the example of many other European countries (United Nations, 2022), which emphasized the importance of the convention. The intent of the Convention of the Rights of Persons with Disabilities is to *"promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."* (United Nations, 2007). One of the main aspects of this is that all people should be able to equally participate in society. In practice, this means that all people should have, for example, equal access to public space and medical aids, but also that people should be able to work and live their life in a way they choose.

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[1] Except for the year 2020, where life expectancy estimates decreased again due to the COVID-19 pandemic.

People with chronic or disabling conditions may experience not only physical health problems, but also mental health issues, reduced quality of life, and an impact on social relationships (Fortin et al., 2006; Haas et al., 2010; Oldenkamp et al., 2013). For people with chronic or disabling conditions, there are not only practical barriers, but also social barriers that limit full participation in society (Vermeij & Hamelink, 2021). This may also hamper people to participate socially. Social participation is not only a goal in itself, but it is also seen in recent policies in the Netherlands as a way to promote self-reliance, self-management and increase patient empowerment. These policies focus on people's self-reliance and mobilizing their social networks, aiming to reduce the dependency of people with chronic or disabling conditions on formal care or support from the government. It remains an important question however, if, how and when the key assumptions behind these policies are actually met. This implies that we need to look into the relationship between having a chronic or disabling condition and informal social capital. From a scientific perspective, we do this by building on the work of (next to many others) Bourdieu (1986), who defines informal social capital as *"the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition.".* From a policy perspective, we will research how informal social capital of people with a chronic or disabling condition is related to different types of healthcare utilization as well.

Informal social capital in relation to the changed policy context in the Netherlands

Many countries face challenges in building sustainable healthcare systems for the future demand for care. The Netherlands provides for an interesting case, since major changes in the healthcare system have taken place since 2006, when a system of which regulated competition is an important basis was introduced (OECD/European Observatory on Health Systems and Policies, 2021).

The first major reform took place in 2006, when the Health Insurance Act (HIA) (in Dutch: *Zorgverzekeringswet*, ZVW) was introduced to cover curative care (Jeurissen & Maarse 2021). From then on, a mandatory basic health insurance was carried out by private insurers and people have been enabled to supplement this basic insurance with extra insurances that provide more coverage (Jeurissen & Maarse, 2021). The system relies on the balance between three players: clients (every resident of the Netherlands), health insurers and healthcare providers (Ministry of Health, Welfare and Sport, 2016; Kroneman et al., 2016). Clients choose their health insurance every year and the idea behind this is that insurance companies compete for customers within a system of regulations that supervise the system (Jeurissen & Maarse, 2021).

Long-term care has been reformed as well, starting with the introduction of the Social Support Act which made municipalities responsible for a greater part of long-term non-residential care (Maarse & Jeurissen, 2016). This act was extended in 2015 with more non-residential long-term care (Maarse & Jeurissen, 2016). The Social Support Act arranges community support, support for informal caregivers and volunteers, prevention and provisions regarding domestic violence, sheltered living arrangements, and help with daily tasks such as cleaning and cooking. Municipalities arrange local general facilities (such as meal services, places to meet each other, sheltered living), but also offer more specific help at home, such as cleaning services. Since 2015, municipalities are also responsible for youth care and help, preventive measures, child protection services and youth probation. Municipalities receive subsidies and can shape their own policies within the national system. The policy assumption is that municipalities are better able to arrange care for their clients and do this more (cost-)efficiently, by amongst other things, helping people through local social networks and the individuals' social networks (Maarse & Jeurissen, 2016).

Aims of this thesis

As addressed before, an important policy assumption behind health system reforms is based on the potential of the self-reliance and social networks of citizens. The assumption implies that informal social capital development could achieve a 'win-win-situation' (by promoting participation, saving costs and providing appropriate care for those who need it). However, knowledge on the relationship between having a chronic or disabling condition and an individual's informal social capital is limited. Although there are studies that show that having a chronic or disabling condition can limit the possibilities to attain and maintain informal social capital, there are limitations in existing literature. Many studies are focused on samples that are specific in nature, meaning that these results cannot be generalized to a full target population of adults in a country. Also, the concept of social capital is often not mentioned in this line of research, even though it provides a strong theoretical base to better understand the relationship between having a chronic or disabling condition and social participation. On the other hand, there is a line of research that focuses on health outcomes of social capital, investigating for example the relationship between social capital and mortality or survival rates. The majority of these studies have overlooked the fact that having a chronic condition can also be a limitation in maintaining informal social capital (Ferlander, 2007). The main focus of this dissertation is to gain a better understanding of the relationship between having a chronic or disabling condition and informal social capital, including relevant individual level and contextual level factors. We will also look into the relationship between having more or less informal social capital and healthcare utilization (including care from the Social Support Act). We will research these relationships by building on the concept of social capital and the strong theoretical base of this concept in research and using large scale, representative data.

Within this dissertation, our aim is not to evaluate the healthcare policy shifts in the Netherlands, but rather to better understand the relationship between having a chronic or disabling condition and informal social capital *in local and nationwide contexts*. Also, we aim to understand the effects informal social capital of people with a chronic or disabling condition can have on their healthcare utilization. Both insights, and the role of individual and contextual factors, can gain a better understanding of the principles on which the policy (reform) assumptions in the Netherlands are based.

1.2 What do we know about the relationship between informal social capital and chronic and disabling conditions?

The concept of informal social capital

Pierre Bourdieu defined ‘social capital’ as “the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition.” (Bourdieu, 1986). Many researchers have complemented and specified the concept of social capital. For example, bonding and bridging social capital (e.g. Putnam, 2000; Portes 1998; Woolcook 1998) focus on the hetero- or homogeneity of the relationships. Bridging social capital consists of more diverse social networks, while bonding social capital consists of networks with more similarity (socially or for example within the same organization) (Ferlander, 2007). An important extension of the conceptualization of social capital is the distinction first made by Pichler and Wallace (2007) between formal and informal social capital. The concept of formal social capital is mainly based on the work of Robert Putnam (2000), who states that civic participation is important for society as a whole and that there are many advantages for society that come with participation of its residents in formal organizations. Informal social capital consists of social bonds between individuals. It thus entails bonds with friends, family, neighbors et cetera. When looking at most distinctions made in social capital research, the majority focuses on how social ties can be an important asset in life. Social ties can give emotional and practical support or provide people with important information, for example on job opportunities. It is linked to happiness (e.g. Rodriguez-Pose and Von Berlepsch, 2014), labor market outcomes (e.g. Franzen and Hangartner, 2006; Lin et al., 2001) and many other aspects of life. However, to attain social capital, it is also necessary to invest in relationships. For example, not having enough financial means to undertake activities with friends or feeling too ill to leave the house for too long can put a strain on the ability to invest in social relationships.

Previous research on informal social capital and chronic or disabling conditions

Although many scholars have addressed the relationship between health and people's informal social capital, the concept of informal social capital itself is not often explicitly touched upon. Previous literature uses a variety of concepts such as social isolation, social support and social networks but not informal social capital specifically.

First, there is a line of research that presumes negative health outcomes for people with a lack of (informal) social capital, for example mortality, heart disease and dementia (Ferlander, 2007). Some of this work is based on biological mechanisms in which social isolation leads to a stress-response in the body that leads to illness or other negative health outcomes. Others built on the idea of a stress-buffering mechanism, where social contacts provide a 'buffer' with coping mechanisms and social support, which in turn can help to reduce negative effects of stressful life events (Yang et al., 2013). For example, Cornwell and Waite (2009) found that social isolation is negatively related to mental health and physical health in general. Hodgson et al. (2020) identified several physiological factors from prior research that play a role in the development of cardiovascular diseases and risk of mortality. They describe physiological mechanisms related to loneliness such as increased cortisol levels, blood pressure, inflammatory markers et cetera which in turn are related to a higher risk of mortality.

Second, another line of research focuses more on the individual perception and coping mechanisms for dealing with chronic and disabling conditions. In short, it poses that having a chronic or disabling condition puts up barriers in one's social life and in the ability to participate in society. These barriers can be diverse. On the one hand, there are barriers that are due to physical complaints of people with a chronic or disabling conditions. To socially participate might be too tiring or harder due to physical constraints (Haas et al., 2010; Öhman et al., 2013). On the other hand, having a chronic or disabling condition can create constraints in the interaction between people and change relationships. Depending on others for help can play a role in this, because relationships may get less reciprocal over time (Haas et al., 2010). Furthermore, stigmatization of the person with a chronic or disabling condition by their environment can play a role, due to physical appearance or, for example, lack of understanding for the fact that some people who have a chronic or disabling condition are unable to work: Garthwaite (2015) describes this in the case of receiving sickness benefits.

The above research presumes either a 'causal' relationship from a lack of social capital (or loneliness, social isolation et cetera) to negative health outcomes, or the other way around in which having a chronic or disabling condition constraints people to maintain social contacts. It would be naïve to state that these relationships are by definition mutually exclusive. However, in this dissertation we will build upon the latter line of research because it lends itself very well to develop a theoretical understanding of the relationship between having a chronic illness or disability and informal social capital. Even though research often describes the (social) mechanisms that may constrain people who have a chronic or disabling condition to attain social contacts in great detail, studies almost never link this to the concept of informal social capital explicitly. Also, a lot of this research is non-representative, which can mostly not be generalized to larger populations. We will fill these lacunae by (1) linking this knowledge to the concept of informal social capital to contribute to a theoretical framework from which hypotheses can be derived, and (2) test these hypotheses including mediating mechanisms with large scale, representative data. This leads to the first two research questions:

1. *To what extent are there differences between people with a chronic condition and healthy individuals in terms of informal social capital?*
2. *To what extent can the relationship between having a chronic condition and informal social capital be explained or mediated by individual level characteristics?*

As stated before, we will answer these two research questions in three different contexts: (1) the general population in European countries, (2) the Netherlands and (3) in people with a specific chronic illness, namely celiac disease in the Netherlands.

Celiac disease is an inflammatory disease of the small intestine caused by gluten, a protein found in wheat, barley and rye. A gluten free diet is the only acknowledged treatment, and since celiac disease is an autoimmune disease, it cannot be cured (Green & Jones, 2010 and Fasano & Flaherty, 2014). Because having celiac disease comes with strict dietary restrictions, and eating is often a social activity (Higgs and Ruddock, 2020), there has been quite some research on the social and psychological constraints it can pose on people's life (e.g. Lee and Newman, 2003; Rosen et al., 2011; Olsson et al., 2009; Sverker et al., 2009). However, it has not yet been linked to the concept of informal social capital.

Exploring the impact of contexts: differences between countries and Dutch municipalities

We know that the *level* of informal social capital varies in European countries (Gesthuizen et al., 2008; Kääriäinen and Lehtonen, 2006; Scheepers et al., 2002). However, differences in the *relationship* between having a chronic or disabling condition and informal social capital, are not often touched upon in cross-national research. The differences in levels of informal social capital between countries have been attempted to be explained by welfare regimes, however, without conclusive results (van Oorschot and Finsveen, 2010) and without looking at the specific group of people with a chronic illness or disability. Also, social capital is often included as a contextual factor (e.g. Waverijn et al. 2014; Kawachi et al. 1999) and not as an individual-level characteristic that may be different for people in different contexts. These examples of studies show that the role of social contexts in the sense of nationwide or local policies is unclear and not often touched upon, which is a lacuna in previous research. As stated in the previous paragraphs, a goal in recent policies in the Netherlands has been to promote social participation and efficiently mobilize people's informal social capital (Jeurissen and Maarse, 2021; Maarse and Jeurissen, 2016). Therefore, we will research the context of countries and municipalities. We will address this by answering research question 3:

> (3) *To what extent can the relationship between having a chronic condition and informal social capital be moderated by (a) country-level and (b) municipality-level characteristics?*

The role of informal social capital in healthcare utilization of people with a chronic or disabling condition

Having a chronic or disabling condition is related to healthcare utilization. Many studies have looked into these effects for specific (chronic) conditions. For example, McNallan et al. (2013) found that level of frailty in patients with heart failure increases the risk of visiting the Emergency Department and being hospitalized. Simon-Tuval et al. (2011) found that patients with COPD consumed more healthcare than patients without COPD and that other health complaints like having diabetes next to COPD increased this even more. In the Netherlands, research shows that people with several chronic conditions show more general practitioner visits and hospital admissions than people with one or no chronic condition (Hopman et al., 2016; van Oostrom et al., 2014). These are just a few examples of the relationship between having a chronic or disabling condition and healthcare utilization. Often, research on healthcare utilization focuses on one or a few types of healthcare. In this dissertation we will take into account five types of healthcare utilization:

(1) care from the Social Support Act;
(2) four types of care from the Health Insurance Act, namely visits to a medical specialist, general practitioner (GP), paramedical specialist or psychological care.

For each type of healthcare utilization, we research to what extent there are differences between people with a chronic or disabling condition and different levels of physical impairments, answering our fourth research question of this dissertation:

> *(4) To what extent do people with chronic conditions vary in their healthcare utilization, depending on the type of health service provision and their level of physical impairment in the Netherlands?*

Next to promoting participation and informal social capital as a policy goal, reducing (certain types of) healthcare utilization by mobilizing one's informal social capital is also often defined as a desired outcome. As a result, the question becomes prominent if informal social capital plays a role in the utilization of healthcare. Again, there are two lines of research that can help us better understand this relationship. First, research has been carried out on whether informal care can substitute formal care (e.g. Bolin et al., 2008). The idea is that when family, friends or neighbors provide help and informal care, this can reduce the need for formal care. Bolin et al. (2008) found this for home care for the elderly, while when it comes to care by medical specialists informal care was an addition rather than a replacement. We can apply this idea specifically on the Social Support Act, expecting that being able to access the resources from a social network reduces the need for formal support from the Social Support Act (such as cleaning or cooking services). Prior research shows that contact with neighbors (but not contact with friends or family) can decrease the likelihood of using care from the Social Support Act (Berker et al. 2021). Also, until now it appears that mostly socio-economic indicators, on which budgets for local policies within the Social Support Act are based, explain the use of services within the Social Support Act (Ooms, Sadiraj and Pommer, 2017). However, it was also stated that social indicators deserve more detailed attention in future research (Ooms, Sadiraj and Pommer, 2017).

Other studies have focused on the aspect of informal social capital that may increase healthcare utilization. For example, people's social capital may improve knowledge about healthcare providers and services (Andersen, 1995; Deri, 2005) or offer practical support to visit healthcare providers. Prior research has found a positive relation between social capital and visiting medical specialists (Fjaer et al., 2017). We apply this idea to the other types of healthcare utilization that are included in the Health Insurance Act in the Netherlands. Another line of research focuses on how people who experience loneliness are more likely to use different types of healthcare services. Burns et al. (2020), however, point out that only few studies took into account health status and health behaviors sufficiently and many only found small effects. Burns et al. (2020) found a relationship between loneliness and GP visits (also when controlled for health), but only for older women.

To summarize, we see two possible mechanisms of informal social capital that may play a role in the relationship between having a chronic or disabling condition and healthcare utilization: (1) it may reduce the use of *Social Support Act (SSA)-care* because informal social capital can take over (some of) these tasks and (2) it may increase the use of Health Insurance Act (*HIA)-care* by offering practical support and knowledge about healthcare services. Since health status (in our case having a chronic or disabling condition) is an important determinant for the need for healthcare and healthcare utilization, the effects of informal social capital may be different for people who have different levels of impairment due to their chronic or disabling condition. To the best of our knowledge, no research has been carried out in the Netherlands that analyzes the utilization of different types of healthcare services in relation to the informal social capital of people who have a chronic or disabling condition and linking this with social policy contexts. We set out to fill this lacuna in our knowledge by answering the fifth and last research question of this dissertation:

(5) To what extent does informal social capital moderate the relationships between level of impairment in people with a chronic condition on the one hand, and utilization of the different types of healthcare services on the other in the Netherlands?

1.3 Theoretical framework

Having a chronic or disabling condition and informal social capital

In theories about social capital, it is generally acknowledged that you need certain resources in order to obtain and maintain social capital. You generally do not ‘just’ have friends or other social ties. Some resources are necessary in order to keep in contact. Prior research already identified some of these resources. For example, income or education (Berkman and Kawachi, 2000; Gesthuizen et al., 2008; Tigges et al., 1998) are known to foster the access to informal social capital. Social activities often (but not always) require a financial component, like going out for dinner or drinks. Even cooking for friends at home often involves higher expenses compared to only cooking for oneself, which can be difficult on a lower income. Furthermore, years spent in education are years in which a lot of social bonds are built. The longer the educational career, the more likely it is that someone has entered more social networks. So, the general proposition that we start from is: the more resources people have, the more informal social capital they can obtain and maintain.

A resource that can be seen as important in light of informal social capital as well, is health or health status (Hogan et al., 1993). In order to maintain social contacts a certain level of mobility and energy is necessary to visit social contacts, go out together or (sometimes) to be able to have a reciprocal relationship (Haas et al., 2010). A lack hereof is a constraint to maintain informal social capital. Chronic and disabling conditions can also pose constraints in acquiring informal social capital due to stigma and prejudice (Joachim and Acorn, 2000). Thus, we pose that having a chronic or disabling condition can set restrictions on informal social capital – and therefore can actually be seen as lack of a resources that is important in obtaining and maintaining informal social capital (chapter 2 and 3).

In chapter 4 we will focus on celiac disease as one specific chronic condition. In this specific disease, the gluten free diet can be experienced as restrictive (Hall, Rubin & Charmock, 2009) and may have a negative impact on informal social activities (e.g. eating outside the home (Lee & Newman, 2003)). This may reduce opportunities to socialize since social events often involve enjoying food together. Also, people with celiac disease may experience difficulties such as a lack of physical health, stigmatization, the feeling of being a burden to others or other negative feelings related to celiac disease (Smith & Gerdes, 2001; Wahab et al. 2002; Faulkner-Hogg, Selby & Loblay, 1999; Hallert et al. 1998; Olsson et al. 2009 and Sverker et al. 2005).

Mediators on the individual level

It is likely that having a chronic or disabling condition affects specific dimensions of health, that in turn can pose restrictions on someone's ability to meet with friends, relatives, neighbors, colleagues or others. First, having a chronic or disabling condition is related to having *physical complaints*. As described above, we pose that this can be one of the key factors that constrain the ability to invest in informal social capital, because it may hamper one's mobility and, consequently, the ability to go out and socialize (e.g. Haas et al., 2010). Second, physical and mental health are known to be strongly related (Orhnberger et al., 2017). This relationship is complex because both physiological and social factors play a role (Liew, 2011). In qualitative studies it is, for example, described that patients experience a loss of their old lives and identity, physical restraints that withhold them from living the life they would like and worry about the future and prognosis of their condition which can cause anxiety or depression (DeJean et al., 2013). Other studies have shown the relationship between having a chronic or disabling condition and *depression* as well (e.g. Moussavi et al. 2007; Patten et al., 2001). Third, it is known that having a chronic or disabling condition is related to the way people rate their own health (*subjective health)*. When people report a lower subjective health, they may find it more difficult to socialize. A lower subjective health has also been linked to various forms of social capital in prior research (Almgren, Magarati & Mogford, 2009 and Pollack & Von dem Knesebeck, 2004).

Another factor that is known to be related to having a chronic illness or disability is income (van Agt et al., 2000). On the one hand, having a chronic or disabling condition may reduce opportunities to work. On the other hand, having a chronic or disabling condition may involve an increase in medical costs. This can make it harder for people with a chronic or disabling condition to make ends meet (van Agt et al., 2000). As mentioned earlier, financial resources are related to having higher levels of informal social capital by being able to invest in their relationships (Tigges et al., 1998). We therefore take into account not income, but how well people can make ends meet (or *subjective income*).

We thus state that having a chronic or disabling condition can be seen as a lack of resources that can be invested in informal social capital, limiting people to attain and maintain informal social capital. We also pose that having a chronic or disabling condition is related to other dimensions of health and to the extent in which people can make ends meet, and with this a lack of resources that may pose restrictions on the ability to attain and maintain informal social capital. Thus, we will test whether these factors mediate the relationship between having a chronic or disabling condition and informal social capital in chapter 2, 3 and 4.

Moderators on the contextual level

Since many contemporary governments focus on self-reliance and the mobilization of one's social capital in order to manage the care (and costs of care) for people who have a chronic condition, the question arises to what extent governments can promote informal social capital, particularly for those people who have a chronic or disabling condition.

Country level moderators

To provide a theoretical framework for this, we first look at European countries and the distinction first made by Esping-Andersen (1990) in types of welfare regimes. Esping-Andersen (1990: 21-22) states that the different types of welfare states have differential policies to compensate individuals for a (temporary) lack of resources to maintain a livelihood without reliance on the market, i.e., decommodification. Several others have contributed to the distinction in these welfare regimes as well (Eikemo et al., 2008; Bambra and Eikemo, 2008; Arts and Gelissen, 2002; Trifiletti 1999; Fenger, 2007). This results in the following types of welfare regimes (from the highest to lowest level of decommodification): the (social democratic) Scandinavian regime, the (conservative-corporatist) Bismarkian regime and the (liberal) Anglo-Saxon regime. Next to these initial distinctions, there is the Southern regime (characterized by amongst other things a high degree of familialism and moderate decommodification), the former USSR regime (with the lowest level of decommodification of all other types) and the post-communist regime (with many similarities to the former USSR regime, but with a shift to marketization, decentralization and a higher amount spent on health and social protection).

Municipality level moderators

This typology can be applied to Dutch political parties at the municipality level as well, except for the Southern and Eastern European typologies. The different political parties all promote a different level of decommodification, and thus mirror the descriptions of the welfare states as described above. In the Netherlands, the Socialist Party (SP), the Labour Party (PvdA), and Green Left (GroenLinks) can be identified as parties who prefer redistribution of income to the greatest extent. They best fit the description of social-democratic regimes (Esping-Andersen, 1990). The Christian Union (Christen Unie), Christian Democratic Appeal (CDA) and the Reformed Political Party

(SGP) are all parties with a Christian identity. Redistribution of income is less far-reaching as preferred by social-democratic parties. These parties best fit into descriptions of conservative corporatist regimes (Esping-Andersen, 1990, Bambra & Eikemo, 2008). The People's Party for Freedom and Democracy (VVD) and Democrats 66 (D66) identify as liberal parties. Their policies focus on a reliance on the market and prefer the least of all the parties to redistribute income into social security policies. Local parties mostly act pragmatically, not following the ideologies that are present in national politics, but explicitly connecting to the local needs of citizens in the municipality (Janssen & Korsten, 2003; Boogers & Lucardie, 2007), so these are best seen as a separate group of political types.

We expect that the level of decommodification can make a difference for people who have a lack of resources that can be invested in informal social capital due to a chronic or disabling condition. The more people with a chronic or disabling condition are compensated by a government, the more resources are left to invest in informal social capital. We thus expect that people who suffer from a chronic or disabling condition experience a lack of resources that can be compensated in favor of their informal social capital, but that this relationship will be different for people who live in a country or municipality with a stronger political focus on decommodification. The more decommodification, the more people may be compensated for their lack of resources, so that they are able to maintain higher levels of informal social capital. We will research this in chapter 2 (countries) and 3 (municipalities).

From chronic and disabling conditions to healthcare utilization: informal social capital as a moderator

When we establish a better understanding of the relationship between having a chronic or disabling condition and informal social capital, another piece of the bigger puzzle deserves attention, namely the relationship between the amount of informal social capital of people who have a chronic or disabling condition and their healthcare utilization. Since the policies include people's social network and municipalities look at the possibilities of the social network of people to provide informal care (Maarse & Jeurissen, 2016), our aim is to provide a better understanding of the relationship between informal social capital and healthcare utilization of people with a chronic or disabling condition. In order to provide a theoretical framework we use the Behavioral Model of Health Services Use. In the Behavioral Model of Health Services Use, originating from the 1960s and later revisited by many (for example Andersen, 1995), health itself and demographic characteristics play an important role. Having health complaints is a very important determinant of healthcare utilization in this model. However, in the Behavioral Model of Health Services Use it is theorized that there are more “enabling factors” that play a role (Andersen, 1995). These enabling factors can be the availability of healthcare personnel, access to health insurance, knowledge about the availability of healthcare, but someone’s social environment (i.e. informal social capital) as well. In the Netherlands, care under the Social Support Act consists of amongst other things help with daily activities, but help by one’s informal social capital is to be requested whenever possible, before relying on the Social Support Act. The idea is that part of this help can thus be carried out by these contacts (i.e. informal social capital). Although health status will probably be the main determinant of healthcare utilization from the Social Support Act, the relationship may be less strong for people with a lot of informal social capital. Care within the Health Insurance Act cannot be carried out partly by social contacts (i.e. informal social capital), since these types of curative care must be carried out by licensed professionals. However, informal social capital may be able to offer practical support to find and enable visits to these professionals (for example transportation from and to a hospital, access to health services). Again, we propose that health status may be positively related to the likelihood of using these types of healthcare – but when people are able to turn to their informal social capital for practical help and support, this may increase healthcare utilization more than for people who have less informal social capital.

Figure 1.1 shows the outline of this dissertation.

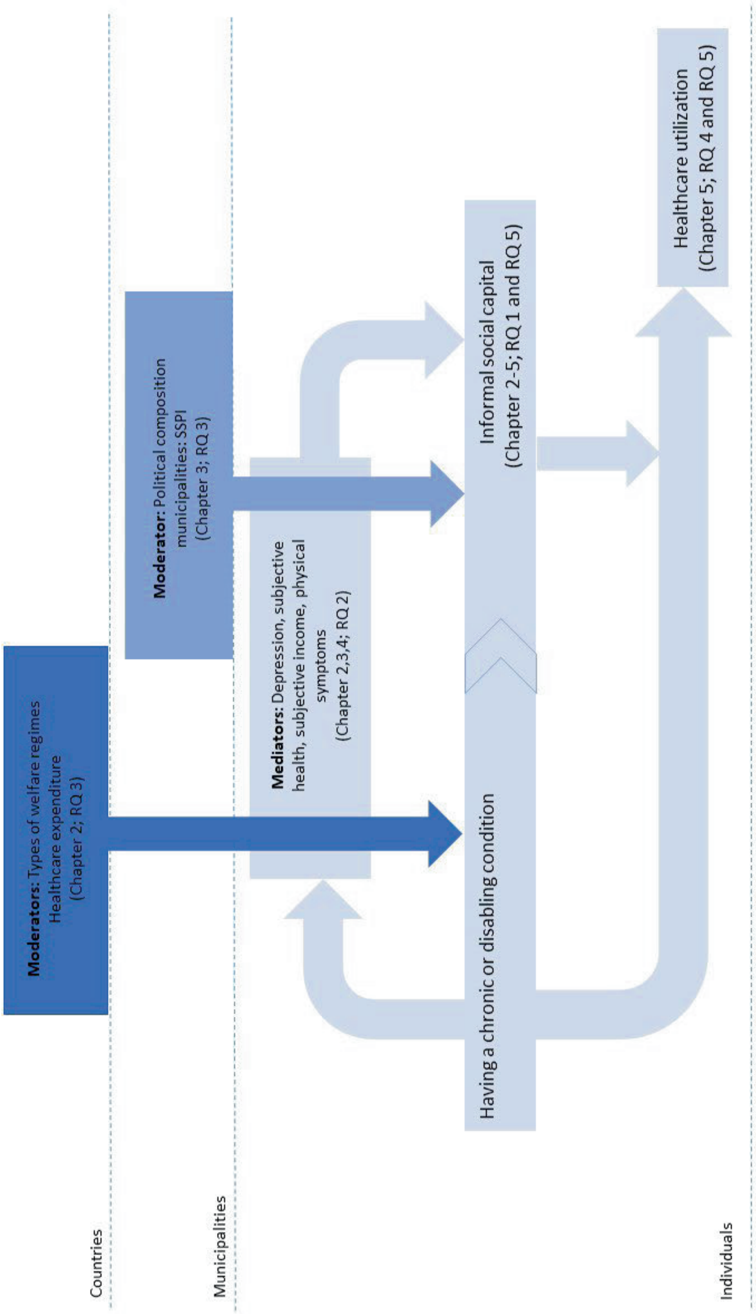

Figure 1.1: *Research model of this thesis*

1.4 Aim and outline of this research

In this dissertation we aim to better understand the relationship between having a chronic or disabling condition and informal social capital, in the light of the growing attention for self-reliance of people who have a chronic or disabling condition. Previous studies mostly focused on health (such as mortality, cardio-vascular diseases etc.) in relation to a lack of informal social capital, i.e. lack of social contacts. Other studies focused on how chronic and disabling conditions may hamper people in their social lives but are mostly based on non-representative samples. The concept of informal social capital, as we use and apply it in this research, is mostly not mentioned explicitly in these studies. We claim that the concept of informal social capital provides a theoretical framework that is very suitable to derive testable hypotheses on the relationship between having a chronic or disabling condition and informal social capital. Also, there are only few studies that take into account the context of people with a chronic or disabling condition in terms of policies that may affect people with a chronic or disabling condition in some way. We will address these lacunae in our knowledge in this dissertation, by building a theoretical framework around the concept of informal social capital and consider health to be a resource that is necessary to be able to invest in informal social capital, attain it and maintain it, using mostly representative and large-scale datasets to test our hypotheses, and by taking into account context-level characteristics. This will be addressed by the following research questions in Chapter 2 to 4:

(1) To what extent are there differences between people with a chronic condition and healthy individuals in terms of informal social capital?
(2 To what extent can the relationship between having a chronic condition and informal social capital be explained or mediated by individual level characteristics?
(3) To what extent can the relationship between having a chronic condition and informal social capital be moderated by (a) country-level and (b) municipality-level characteristics?

The aim of **Chapter 2** is to first build a theoretical framework based on prior research on health and informal social capital. Then we test whether three specific subdimensions of health explain the relationship between having a chronic condition and informal social capital, to what extent this relationship differs between countries in Europe and to what extent the policies in these countries may support their citizens with chronic conditions to maintain their informal social capital.

After this, the question is whether this theoretical framework can also be used to research differences between municipalities within the Netherlands. This is relevant because they gained more responsibilities to arrange parts of the care for their inhabitants in recent years. To what extent do differential policies compensate their inhabitants with a chronic or disabling condition in maintaining their informal social capital? This is the first goal of **Chapter 3**, in addition to testing the individual level hypotheses again.

Chapter 4 focuses on people who have celiac disease or non-celiac gluten sensitivity (NCGS). In this chapter only the individual level hypotheses will be assessed. The aim of this chapter is to gain a better understanding of this particular chronic condition and its relation to people's informal social capital, since it is considered a chronic condition that generally has a considerable impact on one's social life.

Another aim of this dissertation is to gain knowledge on the impact that informal social capital may have on healthcare utilization. Recent policy changes in the Netherlands were meant to keep the system durable and to make it more affordable, while also improving quality. However, knowledge on the role of informal social capital in different types of healthcare utilization in the Netherlands is scarce. Therefore, we will answer the following two research questions:

(4) *To what extent do people with chronic conditions vary in their healthcare utilization, depending on the type of health service provision and their level of physical impairment in the Netherlands?*

(5) *To what extent does informal social capital moderate the relationships between level of impairment in people with a chronic condition on the one hand, and utilization of the different types of healthcare services on the other in the Netherlands?*

Answering these research questions is the aim of **Chapter 5**, where we will research to what extent the level of physical impairment of people with a chronic or disabling condition determines their healthcare utilization.

Additionally, we will look into the possible moderating effects of informal social capital.

1.5 Data, measurements and analyses

In order to answer the research questions, we use several large-scale datasets. In this paragraph we describe the data, measurements and analyses used in this dissertation. Table 1.1 summarizes the most important characteristics related to the data and methodology of all studies.

1.5.1 Data

European Social Survey (Chapter 2)

The European Social Survey is a cross-national survey that has been carried out every other year since 2001. Respondents of around thirty countries participate in this study. Samples of the adult population of people 18 years or older of each country are representative and selected by strict at-random probability methods. All stages of sampling, data gathering and translation of the questionnaires are governed by expert groups. The European Social Survey contains many measurements of the behavior, opinions and attitudes of the respondents, and is also well suited for our research as it contains measurements of suffering from a chronic or disabling condition and informal social capital (meeting socially with neighbors, friends, colleagues and family). The main advantage is the comparability of the data across countries and the high quality of the data. We used data from wave 6 (2012).

National Panel of people with Chronic illness or Disabilities (Chapter 3 and 5)

The National Panel of people with Chronic illness or Disabilities is a representative and nation-wide panel in the Netherlands governed by the Netherlands Institute of Health Services Research (Nivel). The panel consists of people of 15 years or older, who live independently and have a medically diagnosed chronic condition and/or a physical disability. Members of the panel are recruited via general practitioners and population screenings by Statistics Netherlands. The aim of the panel is to monitor the consequences of living with a chronic condition or a disability. Panel members receive questionnaires twice a year (Menting et al., 2019). This panel specifically focuses on people who have a chronic condition or disability and contains data on many aspects of amongst other things their health, healthcare utilization and participation in society. We used data of 2017 (Chapter 3) and 2018 (Chapter 5).

Dutch Healthcare Consumer Panel (Chapter 3)

The Dutch Healthcare Consumer Panel consists of almost 12,000 members of 18 years or older at the moment of the study. Members are recruited in two ways: (1) by random selection from address files purchased from a national address supplier and (2) via general practices that are included in the Nivel from the Primary Care Database[2]. The aim of this panel is to measure: (1) opinions on healthcare, (2) knowledge about healthcare, (3) experiences with healthcare and (4) expectations of healthcare. Panel members receive about three questionnaires per year (Brabers et al., 2015; Brabers, 2018; Nivel, 2020). We used data from 2017.

For the second study of this dissertation (Chapter 3), the National Panel of people with Chronic illnesses or Disabilities and the Dutch Healthcare Consumer Panel were combined. The fact that many questions in these panels are the same, is a major advantage of these datasets. Combining the two high quality data sources enabled us to compare people with a chronic condition with the general population.

Questionnaire for people with celiac disease/NCGS (Chapter 4)

To research this specific chronic condition, a questionnaire was sent to members of the Dutch Celiac Association in 2016. In order to compare the informal social capital of people without celiac disease or NCGS to the people who do have celiac disease or NCGS, nonrandom convenience sampling was used. Every respondent was asked to send another questionnaire to one friend or acquaintance. The goal of this approach was to find a healthy control group, which resembled the celiac disease or NCGS patients on some important characteristics such as gender and age, but were not so close to the respondent that a bias would occur considering informal social capital.

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[2] For more information, see: https://nivel.nl/en/nivel-primary-care-database

Table 1.1. Summary of the approaches of the different studies in this dissertation

Chapter	RQ	Main relationship	Operationalization chronic condition	Mediators	Moderators	Data	Analysis
2.	1, 2, 3	Chronic conditions - informal social capital	Hampered in daily activities by long standing illness/ disability/ infirmity/mental health problem	Feelings of depression Subjective health Subjective income	Welfare regimes Healthcare expenditure	European Social Survey, 2012 World Bank	Random intercept multilevel regression analyses Contextual moderation
3.	1, 2, 3	Chronic conditions - informal social capital /neighborhood participation	Chronic illness (officially diagnosed) and/or disability (score on 27 items): no impairment – severe impairment	Feelings of depression Subjective health Subjective income	Social Support Policy Index	National Panel of people with a Chronic illness or Disability (NPCD) Dutch Healthcare Consumer Panel (DHCP)	Random intercept multilevel regression analyses Contextual moderation
4.	1,2	Celiac Disease/ Non-celiac gluten sensitivity - informal social capital	Self-reported diagnosis and self-reported medical tests	Feelings of depression Subjective health Physical symptoms Other chronic conditions	-	Survey among members Dutch Celiac Disease Association and non-random convenience sample to find control group	Linear regression analyses
5.	4, 5	Chronic conditions - healthcare utilization	Chronic illness (officially diagnosed) and/or disability (score on 27 items): no impairment – severe impairment	-	Informal social capital	National Panel of people with a Chronic illness or Disability (NPCD)	Logistic regression analyses

World Bank (Chapter 2) and government data (Chapter 3)

In Chapter 2 and 3, we test cross-level interaction hypotheses on the country- and municipality level. On the country level we used the division first made by Esping Andersen (1990) and later complemented by others (Eikemo et al. 2008; Bambra and Eikemo, 2008; Trifiletti, 1999) to distinguish between different welfare regimes. For this purpose, no additional data source was needed. However, we also included healthcare expenditure (the percentage of gross domestic product (GDP) spent on health care) per country, which was derived from the World Bank (2012).

To acquire comparable data for municipalities was a bigger challenge. When the research took place, no complete data on healthcare expenditure within the Social Support Act was available. Although some of the municipalities in the Netherlands participated in inquiries on this topic, not enough municipalities responded for the data to be suitable for this research. Also, no concise data was available on the policies of municipalities regarding the interpretation of the Social Support Act. What was available, however, was the political composition of the councils of these municipalities in 2017. The composition of all the Dutch municipality councils is published publicly on the website of the Dutch government. The publication of the data is commissioned by the Ministry of Interior and Kingdom Relations and contains (amongst other things) information about all councilors per municipality, including their political party. A municipality can have a diverse composition, with councilors of various political parties. We constructed an index (Social Support Policy Index) that took into account this variation and provides a proxy for the level of decommodification that is preferred by the different political parties in the particular municipality (see Chapter 3).

1.5.2 Measurements

By using different datasets, it can be challenging to find comparable measurements of key variables. In this dissertation, the measurements of informal social capital and many background characteristics are very comparable because the questionnaires use validated questions and scales. Informal social capital was measured by the question "*How often do you socially meet with (1) (grand)children or relatives, (2) friends, (3) colleagues or (4) neighbors*", where only the specific categorization of types of social contacts sometimes differed slightly, for example, sometimes colleagues were not included and contacts with family could be measured in only one category or in two (‘(grand)children’ and ‘relatives’ or only ‘relatives’).

Our independent variable (having a chronic condition or impairment), however, is less similar over the different studies in this dissertation. In the European Social Survey, respondents were asked to what extent they were hampered in their daily activities by an illness, disability, infirmity or mental health problem. The National Panel of people with Chronic Illnesses or Disabilities is, as the name implies, focused on this specific group of people and therefore contains more information about the nature of people’s illness or disability. The data contains information on two dimensions. First, it is known whether someone has a chronic illness or not (diagnosed by a medical professional). Second, respondents are asked to what extent they face difficulties in daily activities (27 items, frequently used to measure self-reported level of impairment (de Klerk et al., 2006)). Many people in the data set have a chronic illness and impairment, but the two do not necessarily overlap: one can have an impairment without a chronic condition, or have a chronic condition without an impairment. In Chapter 3 and 5 we elaborate further on this and the specific choices we made for in- or exclusion of respondents based on this information. In chapter 4 we only focus on people who have celiac disease (or NCGS), which is typically a chronic condition in which often relatively few physical complaints are present after treatment (gluten free diet). However, it is considered a chronic condition that induces challenges on people’s social lives.

In addition, many different words are used to describe health constraints: chronic conditions, chronic illnesses, impairments and disabilities et cetera. In the variety in terminology, we want to shortly address this with regard to the papers in this dissertation. The preferred terminology has changed significantly over the years. For example, nowadays we refer to people *who have* a certain (chronic) condition because the chronic condition is just one aspect of a person. Second, there is a large variation in what is considered a chronic condition in terms of what conditions are included or not and how long it should be present to be considered “chronic” (Bernell and Howard, 2016). In this dissertation we aim to use terms that fit the data best. However, sometimes it is necessary to also be somewhat pragmatic and refer more generally to the different types of health complaints people may have.

1.5.3 Analyses

This dissertation contains two studies where contextual factors play an important role and two where this is not the case. For each study, we aimed to determine the methodology that was most suitable for research questions and available data. This means that we carried out multilevel analyses for chapter 2 and 3, in which we specifically focus on the role of governments and municipalities on the question to what extent a chronic condition is related to informal social capital. Linear regression analyses would not do justice to the nature of the data, where individuals are nested in either countries or municipalities, and the fact that we aim to test hypotheses on this level. To test our mediation hypotheses, we use mediation analysis (Hayes, 2014).

In chapter 4 and 5, we use data and test hypotheses on only one level. To this end, we used linear regression analysis (chapter 4) and logistic regression analysis (chapter 5) to test our hypotheses depending on the measurement of the dependent variable (in this case: informal social capital and healthcare utilization).

1.6 Findings

Research Question 1: the informal social capital of people with a chronic condition

This paragraph answers the first research question of this dissertation:

> *(1) To what extent are there differences between people with a chronic condition and healthy individuals in terms of informal social capital?*

We researched this in samples of (a) European countries, (b) Dutch municipalities and (c) people with celiac disease. When we look at the findings in Chapter 2, 3 and 4, it is clear that poor health can be a hindrance when it comes to attaining and maintaining informal social capital. In almost all European countries, people who feel hampered by a chronic or disabling condition have less informal social capital than people who do not feel hampered by a chronic or disabling condition. In the majority of European countries the same pattern was shown which makes this a robust finding. People who are not hampered by a chronic or disabling condition have the most informal social capital, while people who are hampered to some extent have less informal social capital. In addition, people who are hampered a lot have the lowest amount of social capital. Within the Netherlands, however, (see Chapter 3), this relationship is less pronounced: people who have a severe impairment differ significantly in their informal social capital and neighborhood participation from the general population, but people with less severe levels of impairment do not. In Chapter 2 we found lower variations between people who feel hampered a lot by a chronic or disabling condition and those who feel not at all hampered in the Netherlands compared to other European countries as well. However, another factor that could have contributed to this finding is that, in Chapter 3, we could not identify a control group without a chronic or disabling condition but had to compare with a group of respondents from the general population, which included people with a chronic or disabling condition as well. Differences between the general population and people who have a chronic or disabling condition are probably smaller than between people without and with a chronic or disabling condition (see limitations).

We did not find many differences however, in informal social capital between people who followed a gluten free diet (because of celiac disease or NCGS) and a control group that did not, when controlling for several other characteristics. Feelings of depression and having another chronic condition explained part of the differences we found, but several background characteristics seem more important. This result may be explained by the method of sampling a control group (non-random convenience sampling) (see limitations), by the fact that celiac disease is a chronic condition with relatively low physical constraints (for most but not all people), or by the fact that differences in informal social capital between people with and without a chronic condition in the Netherlands seem to be smaller than in other countries.

In order to find out more about the specific health constraints that play a role in the attainment of informal social capital of people with a chronic condition, we posed a second research question of which we will discuss the conclusions below.

Research Question 2: factors that mediate the relationship between having a chronic condition and informal social capital

In this paragraph we will answer the second research question:

> *(2) To what extent can the relationship between having a chronic condition and informal social capital be explained or mediated by individual level characteristics?*

Research shows that physical health and several other dimensions of health often coincide. This is the case for, for example, mental health (e.g. Moussavi et al., 2007) or the appreciation of one's own health, i.e. subjective health (Pinquart 2001). Thus, in our theoretical framework, we also proposed that having a chronic or disabling condition can influence these other dimensions of health and restrict the resources that can be invested in informal social capital. Our findings show that mainly feelings of depression play an important mediating role in the relationship between having a chronic or disabling condition and informal social capital. We found this in the populations of European countries and in the Netherlands. We also found this for subjective health (in European countries and in the Netherlands).

Another way in which the relationship between having a chronic or disabling condition and informal social capital can be mediated is through subjective income (i.e. to what extent people can make ends meet). Within European countries, we found that having a chronic or disabling condition can negatively influence the extent to which people can live comfortably on their income, which in turn is negatively related to informal social capital. In the Netherlands, we did not find this result (as it was in the expected direction but not reached significance). Possibly, this can be explained by the fact that we compared to the general population, or the specific context of social policies in the Netherlands.

In the specific subpopulation of people with celiac disease, it also appears that feelings of depression plays a role, but demographic characteristics such as age, sex and family composition are more important for the level of informal social capital people have in this subpopulation.

Research Question 3: differences between countries and between municipalities

The third question of this dissertation is:

> *(3) To what extent can the relationship between having a chronic condition and informal social capital be moderated by by (a) country-level and (b) municipality-level characteristics?*

The amount of informal social capital people have differs between European countries and types of welfare regimes. People in Scandinavian regimes have the highest levels of informal social capital. Inhabitants of the other types of regimes have less informal social capital as compared to the Scandinavian regimes in the following order: Southern countries, Bismarkian countries, Anglo-Saxon countries, post-Communist countries and lastly, former USSR regimes (although the difference with Southern and Anglo-Saxon countries compared to the Scandinavian countries did not reach significance).

However, the question was to what extent welfare regimes differ in their ability to compensate for the lack of resources of people who have a chronic or disabling condition. In other words: to what extent does living in one or the other country (or welfare regime) have an impact on the loss of informal social capital of people with a chronic or disabling condition? The findings suggest that, as compared to Scandinavian welfare regimes, post-communist and former USSR regimes compensate people with a chronic illness poorly to maintain informal social capital. People in former USSR countries, post-Communist countries and Southern countries who are hampered by a chronic condition have even less informal social capital than the people that are not hampered by a chronic condition in these regimes, indicating that these regimes compensate people with a chronic condition less to maintain their informal social capital. In Southern countries, people who are hampered a lot by a chronic condition differ from their compatriots without a chronic condition. In these Southern European countries, there is a high degree of familialism (Trifiletti, 1999). We suspect that, when people are impeded to some extent, family can still take care of their relatives. When the need for help becomes more severe, help from family may become insufficient. Thus, people who are hampered a lot by their chronic illness in the Southern regime ‘lose’ more informal social capital.

Healthcare expenditure can foster informal social capital as well: the higher the healthcare expenditure of a country, the higher the amount of informal social capital of the people who live in that country. People who are somewhat hampered by a chronic condition (not people who are hampered a lot) benefit from this even more in countries that spend more on health care.

When we zoom in on the Netherlands, differences in informal social capital between municipalities are less clear than between countries. The political composition of municipalities is also no significant factor for most people with chronic conditions in these municipalities for their informal social capital. However, for people who are hampered severely by their chronic condition, differences regarding their level of informal social capital are smaller in municipalities that have a council with a political composition that focuses more on social support measures.

Research Question 4: Healthcare utilization of people with a chronic condition

In this paragraph we will answer the second research question:

> (4) *To what extent do people with chronic conditions vary in their healthcare utilization, depending on the type of health service provision and their level of physical impairment in the Netherlands?*

People who have a chronic or disabling condition and a certain level of impairment are more likely to use different types of healthcare than people with a chronic condition without impairments. We included these types of care in our analyses: care within the Social Support Act, GP care, medical specialist, paramedical specialist and psychological care. However, having a more severe level of impairment does not automatically increase the likelihood of utilization of the different types of care. For example, GPs are the first professional patients can reach out to when they have a health problem. Therefore, most people in our research have had contact with a GP. This is probably why we do see an increased likelihood of visiting a GP for people who have a chronic condition and impairment compared to people who have a chronic condition and no impairment, however, this likelihood does not increase with the level of impairment. Furthermore, it will depend on the type of chronic or disabling condition what type of care people need or how much it might influence their psychological well-being:

the likelihood of using psychological care does not increase with the level of impairment as well. The types of care that especially focus on the physical component, like (para-)medical specialists, the likelihood of using these types of care does increase with the level of impairment.

Research Question 5: informal social capital and healthcare utilization

The final research question of this dissertation is:

> *(5) To what extent does informal social capital moderate the relationships between level of impairment in people with a chronic condition on the one hand, and utilization of the different types of healthcare services on the other in the Netherlands?*

Informal social capital reduces the likelihood to use psychological care. This is consistent with prior research that shows that emotional well-being is strongly linked with being embedded in social networks (Orhnberger et al., 2017; DeJean et al., 2013; Liew, 2011; Moussavi et al., 2007; Patten et al., 2001). People who have a chronic or disabling condition who have more informal social capital also have a lower likelihood of using care within the Social Support Act. This corresponds to one of the assumptions of the Social Support Act in which people are expected to first rely on their own social network before receiving care from the municipality. Informal social capital is not linked to a higher or lower likelihood of using care from a GP, medical specialist or paramedical specialist. These findings are not different for people with higher or lower levels of impairment, so no moderation effects of informal social capital were found in this research.

1.7 Limitations, recommendations for future research and policy implications

In this final chapter we reflect on a number of limitations of the studies included in this dissertation. The first limitation has to do with the independent variable (having a chronic or disabling condition), which is measured differently in the several chapters. In Chapter 2, people were asked to what extent they were hampered in their daily activities by a chronic or disabling condition (not at all, to some extent or a lot). In Chapter

3, we compared people with a diagnosed chronic or disabling condition with the general population. Although the strength of the data was that the conditions were diagnosed officially and the level of physical impairment was measured extensively, the limitation was that we were not able to compare people with and without a chronic or disabling condition but only could compare them with the general population in which there are some people with chronic and disabling conditions as well. In Chapter 4, we attempted to measure the independent variable as similarly as possible to the measurement in Chapter 2, meaning we attempted to find a reference group of people without celiac disease or non-celiac gluten sensitivity by using non-random convenience sampling. While the strength of this study is that we succeeded in comparing the two groups, the method of non-random convenience sampling posed the limitation that some respondents were not able to comply with all instructions given to them for finding a reference group. This resulted in a small control group with people who often had health problems or food allergies or intolerances other than celiac disease or NCGS as well. Also, respondents in the control group who were asked to participate by other respondents in the reference group were often close to them within their social network. They probably shared some part of their informal social capital, which possibly made this group more similar to the respondents with celiac disease or non-celiac gluten sensitivity than when we would have had access to a control group separate from the respondents with celiac disease or NCGS. In Chapter 5 we used a measurement including only people with a chronic or disabling condition, not compared to individuals without a chronic or disabling condition, so there were no problems with this measurement. Future research can be improved by including more distinct control groups of people without a chronic or disabling condition. In spite of the differences in measurements, we should also acknowledge the high quality of the used data and amongst other things high levels of content validity, due to the previous work of methodological experts developing these measurement (https://www.europeansocialsurvey.org/ methodology/, Beullens et al., 2014, van Hees et al., 2018, Brabers et al., 2015, Brabers and de Jong, 2022).

A second limitation was that the measurement of informal social capital, although very often used in previous research, only focused on the frequency of contact with different people in the social network of respondents. We know, however, that not only the size of one’s social network and the amount of contact with the one’s in this network may be important, but that the quality of the relationships and the resources that these relationships bring, matter as well. The definition of informal social capital as introduced by Bourdieu (1986) also focuses on these resources that may be helpful for individuals. Future research could not only focus on both frequency of social contact with a specified number of relevant members in the social networks of respondents, but also contain more in-depth measurements of the nature of the relationships of individuals (with and without a chronic or disabling condition) and the kind of resources that these members provide. These measurements would improve the content validity and the precision and possibly the reliability.

A third limitation was that the measurement of the contextual variables were sometimes limited. In Chapter 2, we chose welfare regimes as delineated in previous theoretical and empirical studies plus the amount of health care expenditure as a percentage of the national GDP to estimate their direct and moderating effects. In Chapter 3, where we researched possible moderating effects on the relationship between having a chronic or disabling condition and informal social capital in the Netherlands, valid and reliable data on the policies and political composition of municipalities were limited. For example, we would have preferred to know what the exact policies within the Social Support Act were in each municipality or which councilors (with which political views) were responsible for topics most relevant for the aspects of the Social Support Act in this study. Instead, we had to construct a more general measure as a proxy for these policies (namely the Social Support Policy Index), building on the work of Esping-Andersen (1990) and others. It would be worthwhile to carry out this research again, but with more detailed data, directly and validly tapping into SSA policies which, however, would be a challenging task.

Also, it would be worthwhile to look into the relationships researched in this dissertation with longitudinal data, instead of cross-sectional data to get a better understanding of the interplay between health and informal social capital. Could it be that people lose more informal social capital as time goes by? To what extent is this related to their health? This could also give us more insight in how local policies may help people maintain their informal social capital.

Other recommendations for further research and policy

A key finding of this research concerns the contextual effects, indicating that the context in which people with a chronic or disabling condition live in some cases matters for their informal social capital. First, we found that compared to people in Scandinavian countries, people in Anglo-Saxon countries, the former USSR and post-communist countries have less informal social capital. We expected that welfare regimes differ in their policies and ability to compensate for the lack of resources of people with a chronic or disabling condition. In other words: we expected the relationship between having a chronic or disabling condition and informal social capital to be different in the different welfare regimes. We found this for former USSR, post-communist and Southern countries. In these welfare regimes, the relationship between having a chronic or disabling condition and informal social capital is stronger, meaning that people who suffer (a lot) from a chronic condition here, have even less social capital than the healthy people in these countries. Regarding health-care expenditure, we found that as countries spend more on health care, the level of informal social capital of their inhabitants is higher. This relationship is even stronger for people who are hampered ‘to some extent’ by a chronic condition.

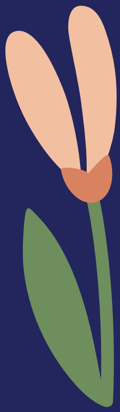
In municipalities in the Netherlands, we found little differences in the relationship between having a chronic or disabling condition and informal social capital. Despite this, it appears that in municipalities with a higher SSPI-score differences in informal social capital are smaller for people with a severe impairment.

These context findings ask for more in-depth knowledge about the specific ways in which local governments may compensate people with a chronic or disabling condition that help maintain informal social capital. Future research could therefore focus on researching *regional differences* in other countries. Here, it would be worthwhile to compare countries that are similar to the Netherlands in some respect. For example, this could be countries where part of healthcare and social policies are decentralized to the regional level.

A second key finding is that people with a chronic or disabling condition with more informal social capital (regardless of the severity of possible physical impairments) use less health services that are provided in the Netherlands that are defined in the Social Support Act. At the same time, this dissertation shows that maintaining the *level* of informal social capital of people with a chronic condition is not self-evident. Future research could build upon this by looking into the nature and actual *use* of social capital as a potential resource (Bourdieu, 1986). This draws back on the policy assumptions we mentioned earlier, on *how* people’s informal social capital can improve their self-reliance and how municipalities can strengthen people's network. Van Middendorp (2022) recently found that for people who use debt assistance, the social network is not always of help, which may be due to the homogeneous composition of their informal social capital and its concomitant (lack of) resources (for example because they lack knowledge about finances as well). Also, Kromhout et al. (2020) stated that with the health policies in the Netherlands focusing too much on self-reliance and reliance on one's (informal) social capital and tend to forget that this is not always feasible. Not only because a social network may be lacking for some people, but also because the people who are present, are not always able to help or lack the resources to help out others in their social network. More knowledge is necessary about the *type* of resources available in the social networks (i.e. social capital) of people who have a chronic or disabling condition, the ways in which these can be fostered, and the ways they can call upon their informal social capital for help if needed. This may help municipalities to arrange more specific care suited to the needs and capabilities of their inhabitants.

CHAPTER 2

Chronic illness and informal social capital: Individual level mediators and country-level moderators



A slightly different version of this chapter has been published as:

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Vis and van de Rozenberg wrote the manuscript and conducted the analyses. Scheepers substantially contributed to the manuscript. The study has also benefitted from the insightful comments of several anonymous reviewers.

Abstract

This study investigates whether there are differences in informal social capital between people with a chronic illness and healthy individuals. We also test to what extent this relationship is mediated by individual characteristics and moderated by country-level characteristics. In contrast to previous research, we use representative and high-quality data from the European Social Survey of 2012 as well as multilevel analysis. Our results demonstrate that chronically ill people have less informal social capital, all across Europe. Individual characteristics, including depression, subjective health, and perceived income, mediate this relationship almost fully. Welfare regimes and the amount of money countries spend on health care moderate the relationship between chronic illness and informal social capital.

2.1 Introduction

Chronic illnesses are one of the major causes of mortality in Europe (Busse et al., 2010). The World Health Organization defines chronic illnesses as: ‘Diseases of long duration and generally slow progression’ (ECDA, 2015). This concept comprises different chronic illnesses such as heart diseases, diabetes, inflammatory bowel diseases, mental illnesses, and many others. Such chronic illnesses hamper the daily lives of many people in terms of informal social capital, that is, meeting friends, relatives or colleagues, which is acknowledged by the European Commission for Public Health (https://ec.europa.eu/health/).

However, our knowledge on the extent to which chronic illnesses hamper informal social capital is limited, that is, mostly based on small, non-representative samples from the United States (Charmaz, 1983; Kawachi et al., 1996). Haas et al. (2010) used a large sample of adolescents and found that poor health increased social isolation and hence, decreased informal social capital. To the best of our knowledge, there are only two studies really based on representative national samples that focused on this relationship – studies that actually provided evidence that those who are restricted by chronic illnesses enjoy less informal social capital (Tijhuis et al., 1998; Oldenkamp et al., 2013). However, in influential studies, the relationship between chronic illnesses and social capital is conspicuous by absence (Portes, 1998; Putnam, 2000). Moreover, even in those that focus on the relationship between (restrictions in) health and social capital (Berkman and Kawachi, 2000; Kawachi et al., 2008; Smith and Christakis, 2008), this relationship is barely touched upon.

In this contribution, therefore, we set out to fill this lacuna in our knowledge in several ways. First, we describe the relationship between chronic illness and informal social capital. Therefore, we propose to assess to what extent chronic illness hampers informal social contacts in daily life rather than the other way around (as was done in previous research), particularly so because this domain is underexplored, as argued above. Second, we do so in a wide range of European countries based on representative samples, using the European Social Survey (ESS, 2012), as an improvement compared to previous research. Third, we set out to explain the relationship between chronic illnesses and informal social capital, proposing and testing mediators. Fourth, we assess whether national characteristics, for example, welfare regimes and health care expenditure, affect informal social capital in European countries (following up on previous research by Kääriäinen and Lehtonen, 2006); and if so, we set out to find to what extent the particular national characteristics of these countries may differentially compensate people suffering from chronic illnesses to continue to access their informal social capital. Therefore, we use multilevel analyses to test whether these national characteristics moderate the relationship between chronic illnesses and informal social capital.

Consequently, our research questions are as follows:

1. *To what extent are there differences between people with a chronic illness and healthy individuals in terms of informal social capital?*
2. *To what extent can the relationship between chronic illness and informal social capital be explained by individual level mediators?*
3. *A: To what extent do these differences between chronic illnesses and informal social capital vary across European societies? B: And, if so, are these moderated by country characteristics?*

2.2 Theories and hypotheses

Previous research on social capital often distinguishes formal and informal social capital (Pichler and Wallace, 2007; Savelkoul et al., 2011). We only focus on informal social capital here. The groundwork for the definition of informal social capital was laid down by Bourdieu (1986) and is complemented by many others. Informal social capital mainly consists of informal bonds between people (Pichler and Wallace, 2007).

It is generally proposed that certain resources, such as income and education, affect different forms of social capital (Berkman and Kawachi, 2000; Gesthuizen et al., 2008); people with a higher income can have better access to social capital because they have more economic means to invest in relationships (Tigges et al., 1998). Also, education fosters social capital through socialization at school and within social networks (Gesthuizen et al., 2008). When pursuing this line of thought, we propose that health is another kind of resource; vice versa, a lack of health can reduce opportunities to invest in social contacts. Hogan et al. (1993) argue that good health is a resource whereas bad health is a constraint in the context of social exchanges. Haas et al. (2010) state that people with a chronic illness are often hampered in their physical activities and thus have to cope with chronic constraints to meet others. This was also previously found by Charmaz (1983) and Fougeyrollas (2000). Furthermore, Haas et al. (2010) also state that, for people with a chronic illness, reciprocity is harder to maintain in social relationships because of a lack of energy. Therefore, we overall expect the following.

1. The more people are hampered in their daily activities by any chronic illness, the less informal social capital they have.

2.2.1 Individual level mediators

The lack of resources of people with a chronic illness can also affect other dimensions of health such as depression and subjective general health. Several studies showed that depression is more common among people with a chronic illness (e.g. Moussavi et al., 2007). Moreover, symptoms of depression have been linked to various measures of social capital, such as memberships of and participation in groups (Lin et al., 1999; Pollack and Von dem Knesebeck, 2004). People who are hampered by a chronic illness are more likely to experience feelings of depression, which may reduce their ability to maintain informal social contacts.

2. The negative relationship between chronic illness and informal social capital can be (partly) explained by (feelings of) depression.

A second mediator that we take into account is subjective general health. Liang (1986) and Pinquart (2001) showed that chronic illness is strongly associated with a lower subjective health, which in turn is related to informal social capital (Pollack and Von dem Knesebeck, 2004). Thus, people who are restricted by a chronic illness may also evaluate their subjective health as being worse, which may reduce informal social capital.

3. The negative relationship between chronic illness and informal social capital can be (partly) explained by a lower subjective general health.

People with a chronic illness are also more vulnerable to poverty. This is partly the case because these people may have fewer opportunities to work, reducing their income. Moreover, people with a chronic illness often have higher medical costs, which can make it harder to make ends meet (Van Agt et al., 2000). People with a lower income and higher (medical) costs probably will live less comfortably on their income and have fewer economic resources that can help maintain informal social capital (Tigges et al., 1998).

4. The negative relationship between chronic illness and informal social capital can be (partly) explained by a lower income.

2.2.2 Contextual moderators

Previous research has shown that countries differ in their amount of informal social capital (Gesthuizen et al., 2008; Kaäriänen and Lehtonen, 2006; Scheepers et al., 2002). To provide a theoretical understanding of the differences in the relationships between chronic illness and informal social capital across European countries, we follow the rationale on previous distinctions between types of welfare states: Scandinavian, Anglo-Saxon, Bismarkian (Esping-Andersen, 1990); South European (Bonoli, 1997; Ferrera, 1996); and former USSR-type regimes and post-communist European-type regimes (Fenger, 2007). The underlying rationale, provided by Esping-Andersen (1990: pp.21–22), is that these welfare states have differential policies with regard to (health-care) policies and funding spent on health care to compensate particular individuals for a (temporary) lack of resources to maintain a livelihood without reliance on the market, that is, decommodification.

The (social democratic) Scandinavian regime is characterized by policies that promote social equality through a redistributive social security system (Eikemo et al., 2008) and reduce the influence of the market on distribution (Bambra and Eikemo, 2008). The generous universal and highly redistributive benefits depend little on individual contributions, although recent changes reduced these benefits to some extent (Arts and Gelissen, 2002; Burström, 2015). These redistributive benefits may compensate for the reduced resources of chronically ill people in these countries, reducing differences between them and healthy people in terms of social capital.

The (conservative-corporatist) Bismarkian regime is characterized by a moderate level of decommodification and limited redistribution (Esping-Andersen, 1990). The principle of subsidiarity implies that the state will only interfere when the family's capacity to serve its members is exhausted (Bambra and Eikemo, 2008). This limited redistribution may also compensate for reduced resources of chronically ill people in these countries in terms of social capital, but less so than in countries belonging to the Scandinavian regime.

The (liberal) Anglo-Saxon regime is characterized by means-tested assistance and modest social insurance plans. There is little redistribution of income in the social security system (Esping-Andersen, 1990). Social rights are rather poor (Scheepers et al., 2002) and recipients are usually stigmatized (Bambra and Eikemo, 2008). This regime has the lowest level of decommodification; the dominance of the market is encouraged by guaranteeing only a minimum and by subsidizing private welfare schemes. This regime may only marginally compensate for reduced resources of chronically ill in terms of social capital, probably far less so than in countries belonging to the Scandinavian regime.

After these initial distinctions, the South European regime (the Latin Rim) has been described as ‘rudimentary’, because the welfare provision is fragmented and consists of diverse income maintenance schemes of varying heights. There is a high degree of familialism, moderate decommodification and modest redistributive effects (Trifiletti, 1999). The health sector, in particular, provides only limited and partial coverage (Bambra and Eikemo, 2008). This regime may (marginally) compensate for chronically ill people, especially in terms of social contacts with family, but less so than in countries belonging to the Scandinavian regime.

After the collapse of the communist system, former member countries in the Union of Soviet Socialist Republics (USSR) were also considered to be distinct welfare regimes; they resemble the conservative-corporatist type when looking at total government expenditures (Fenger, 2007). However, all other governmental programs are below the Western European types. This regime spends the least on health and social protection in comparison to all other regimes. Inequality in these countries is (almost) as high as in the Anglo-Saxon regime (Fenger, 2007). Therefore, this welfare regime is expected to compensate chronically ill people the least compared to all other regimes and to differ the most fromthe Scandinavian regime.

The post-communist European-type regime shows similarities with the former USSR-type regimes, but it can be distinguished because it is clearly more egalitarian. These countries have experienced a shift towards marketization and decentralization (Bambra and Eikemo, 2008). Post-communist European type regimes spend more on social protection and health than former USSR countries. These differences may be due to economic developments over recent decades, which makes this regime more similar to the Bismarkian regime (Fenger, 2007). This regime may marginally compensate for chronically ill people and differ from the Scandinavian regime, but less so than the former USSR-type regime.

Overall, we propose to test an (exploratory) hypothesis on the differential relationships between chronic illness and social capital that may be related to the nature of the welfare state.

5. Informal social capital of chronically ill people will be the highest in Scandinavian welfare regimes; next, it will be somewhat lower in Southern European regimes, Bismarkian regimes, and Anglo-Saxon regimes; then post-communist countries; and then the lowest in USSR countries.

Chronically ill people may have fewer resources than healthy people, in terms of a lower income and higher medical costs (Van Agt et al., 2000), and thus are less able to invest in their social capital. States might compensate for this lack of resources by spending money on health care. When states compensate for medical costs to a high extent, we expect that people have more financial resources left to invest in their informal social capital. Since European states differ in the amount they spend on health care (World Bank, 2011), differences in social capital between healthy people and chronically ill people can be reduced to a different extent in European countries.

6. The more a country spends on health care, the weaker the relationship between individual chronic illness and informal social capital will be.

2.3 Data and methods

This study analyzes high-quality data from the ESS (2012). The ESS, which has been conducted every 2 years since 2002, charts the attitudes, beliefs and behavior of citizens in a variety of European countries. Samples of the population of each country are representative and selected by strict at-random probability methods. All stages of sampling, data gathering and translation of the questionnaires are governed by expert groups. For more information about the ESS data, we refer the reader to the official ESS website (http://www.europeansocialsurvey.org). Wave 6, which is used for this research, contains 29 countries with 54,673 individuals. After the exclusion of all respondents with missing values (except for those on income), the final dataset for our analyses consists of 27 countries and 47,543 individuals.

2.3.1 Individual level characteristics

We measured informal social capital with the question: ‘How often do you socially meet with friends, relatives or colleagues?’. Answer categories were ‘never’, ‘less than once a month’, ‘once a month’, ‘several times a month’, ‘once a week’, ‘several times a week’, and ‘every day’. Previous studies used this variable to measure informal social capital as well (e.g. Savelkoul et al., 2011).

Chronic illness was measured by asking respondents to what extent they were hampered in their daily activities by a chronic illness. Answer categories were ‘not at all’, ‘to some extent’, and ‘a lot’. This item was previously used to indicate chronic health conditions (Erlinghagen et al., 2008).

To examine feelings of depression, we used the Center of Epidemiological Studies-Depression Scale. Respondents were asked to fill in how often they experienced certain feelings over the past week on a 4-point scale (from ‘none or almost none of the time’ to ‘all or almost all of the time’)[1]. This scale of depression has been widely used in research on depressive affect (Shafer, 2006). It was found to have very high internal consistency and adequate test-retest reliability (Chabrol et al., 2001). The Cronbach’s alpha of 0.836 indicated that this is a reliable scale.

We measured subjective general health by the question ‘How is your health in general? Would you say it is “very good”, “good”, “fair”, “bad”, or “very bad”’. This measurement indicates both physical and mental health (Huijts, 2011). Moreover, this measurement was used in several studies as an indicator to examine health (Eikemo, 2010).

To indicate (perceived) income, respondents were asked: ‘Which of the descriptions comes closest to how you feel about your household’s income nowadays? “Living comfortably on present income”, “coping on present income”, “finding it difficult on present income”, or “finding it very difficult on present income”’. We used this question because it measures financial

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[1] For this study, the following items were used: ‘felt depressed’, ‘felt that everything you did was an effort’, ‘sleep was restless’, ‘felt lonely’, ‘felt sad’, ‘could not get going’, and ‘felt anxious’.

constraints (Halleröd and Larsson, 2008; Paugam, 1996), next to actual income.

2.3.2 Contextual variables

We created a variable for welfare regimes by distinguishing six types of welfare states: Scandinavian, Anglo-Saxon, Bismarkian (Esping-Andersen, 1990), South European (Bonoli, 1997; Ferrera, 1996), former USSR, and post-communist (Fenger, 2007). The classification of countries in these regimes can be found in Appendix A.

For health-care expenditure, the percentage of gross domestic product (GDP) spent on health care was retrieved from the World Bank (2011). Descriptives of health-care expenditure can be found in Tables 2.1 and 2.2.

2.3.3 Control variables

We controlled for a variety of resources related to social capital or health in accordance with the existing literature. These were ‘education’ (Cutler and Lleras-Muney, 2006), ‘income’ (Berkman and Kawachi, 2000), ‘marital status’ (Lindström, 2009; Putnam, 2000), ‘having children’ (Gray, 2009; Lin, 2000), and ‘religious attendance’ (Huijts and Kraaykamp, 2011). Also, ‘gender’, ‘age’ (Gray, 2009; Huijts, 2011), and ‘ethnicity ‘(Lin, 2000) were expected to be related to social capital and health and were therefore taken into account.

Education was measured with the use of the ‘International Standard Classification of Education’ scale, which is designed to facilitate cross-cultural comparisons concerning educational levels (UNESCO, 2015). It contains seven categories ranging from pre-primary education to the second stage of tertiary education. Income was classified in 10 deciles, with an added ‘unknown’ category for our missing values on income.

Furthermore, we distinguished ‘people who are married/living together’, ‘divorced’, ‘widowed’, and ‘people who were never together with a partner’. We also took into account whether people have children (who live at home).

Religious attendance was included using a 6-point scale ranging from attending religious services never’ to ‘attending religious services every day’. Gender (1=female), age (15–103), and whether respondents belong to a minority group (1=yes) were taken into account. Descriptive statistics of all variables can be found in Tables 2.1 and 2.2.

Table 2.1. *Descriptive statistics.*

Continuous variables						
	N	**% in category 1**	**Min**	**Max**	**Mean**	**S.D.**
Informal social capital	47,543		1	7	4.760	1.624
Depression	47,543		1	4	1.635	0.546
Subjective health	47,543		1	5	2.263	0.925
Education	47,543		1	7	3.871	1.862
Age	47,543		15	103	48.813	18.418
Health expenditure (country)	47,543		5.7	12.1	8.851	1.748
Categorical variables						
Chronic illness						
• No	35,144	73.9				
• Yes to some extent	9512	20.0				
• Yes a lot	2887	6.1				
Income						
• Decile 1	4399	9.3				
• Decile 2	4786	10.1				
• Decile 3	4348	9.1				
• Decile 4	4228	8.9				
• Decile 5	4018	8.5				
• Decile 6	3899	8.2				
• Decile 7	3767	7.9				
• Decile 8	3515	7.4				
• Decile 9	3029	6.4				
• Decile 10	3179	6.7				
• Unknown	8375	17.6				
Perceived income						
• Comfortable	11,619	24.4				
• Coping	20,447	43.0				
• Difficult	10,460	22.0				
• Very difficult	5017	10.6				
Marital status						
• Together with partner	24,438	51.4				
• Divorced/separated	4844	10.2				
• Widow(er)	4764	10.0				
• Never married	13,497	28.4				
Having children						
• Yes at home	17,879	37.6				
• Yes, not at home	15,978	33.6				
• No	13,686	28.8				
Church attendance						
• Never	16,010	33.7				
• Less often	9721	20.4				
• Only on specific holidays	10,404	21.9				
• At least once a month	4703	9.9				
• Once a week	5069	10.7				
• More than once a week/ every day	1636	3.4				
Gender						
• Male	21,679	45.6				
• Female	25,864	54.4				

Table 2.1. *(continued)*

	N	% in category 1	Min	Max	Mean	S.D.
Minority						
• Yes	44,577	93.8				
• No	2966	6.2				
Political system						
• Scandinavian	9624	20.2				
• Anglo Saxon	4653	9.8				
• Bismarkian	8032	16.9				
• Southern	5673	11.9				
• Former USSR	8134	17.1				
• Post-communist	11,427	24.0				

Source: ESS 2012.

Table 2.2. *Descriptive information on country characteristics.*

	Informal Social Capital	Health care expenditure	N
Albania	4.64	5.70	1149
Belgium	5.06	10.61	1822
Bulgaria	4.66	7.72	2161
Switzerland	5.08	11.05	1462
Cyprus	4.29	7.58	1058
Czech Republic	4.56	7.50	1574
Germany	4.74	11.25	2834
Denmark	5.32	10.87	1613
Estonia	4.18	5.83	2266
Spain	5.23	9.44	1813
Finland	4.98	8.95	2167
France	5.11	11.52	1914
United Kingdom	4.81	9.20	2145
Hungary	3.41	8.03	1884
Ireland	4.43	8.70	2508
Iceland	5.31	9.05	651
Italy	4.98	9.20	762
Lithuania	3.98	6.86	1927
Netherlands	5.39	12.10	1817
Norway	5.50	9.28	1605
Poland	4.09	6.87	1788
Portugal	5.73	10.23	2040
Russia	4.34	6.70	2154
Sweden	5.50	9.49	1771
Slovenia	4.64	8.86	1205
Slovakia	4.72	7.96	1666
Ukraine	4.41	7.30	1787
Total	4.76	8.85	47,543

Source: ESS 2012

2.3.4 Strategies for analyses

First, we tested the bivariate relationship between chronic illness and informal social capital in the different countries with analysis of variance. Results (Table 2.3) showed that there was a significant amount of variation between countries in social capital. We also found that in most countries, the more people are hampered by a chronic illness, the less informal social capital people have. This indicated a robust relationship between chronic illness and informal social capital.

Subsequently, we carried out random-intercept multilevel regression analyses to test our hypotheses. Multilevel analysis takes into account that individuals are nested in countries and random-intercept models take into account possible country differences. Bryan and Jenkins (2016) suggested that the use of multilevel logit models for analysing international comparative data, which include fewer than 30 countries, is problematic. Therefore, a multilevel regression model was determined to be the better choice for analysing the data used in this study. All models are shown in Tables 2.4 (a and b). Additionally, Chi-squared tests demonstrated that random-intercept models fit the data significantly better than fixed intercept models. The intraclass correlation in the empty model shows that 11% of the variation in informal social capital can be attributed to differences between countries.

Model 1 only includes our main independent variable, chronic illness. The second model, Model 2, tests the significance of the bivariate relationships while taking into account our control variables in order to test for spurious relationships. In Models 3–5, we tested our mediating hypotheses by adding the mediators, one by one. Thereafter, we added all mediating variables simultaneously in Model 6. Models 7–10 analyzed our cross-level interaction hypotheses. We investigated the main effect of welfare regimes on informal social capital in Model 7. Subsequently, we added relevant cross-level interaction terms concerning welfare regimes in Model 8. The same procedure was followed for health-care expenditure in Models 9 and 10. In Model 11, all country-level characteristics (main effects and interaction effects) were added simultaneously. All analyses were performed with the use of IBM SPSS Statistics 19.

Table 2.3. *Differences in informal social capital per country.*

Country	Healthy people	Hampered to some extent	Hampered a lot	F
Sweden	5.62	5.25	4.90	20.860***
Denmark	5,41	5,15	4,71	13,986***
Finland	5,06	4,85	4,69	8,599***
Iceland	5,34	5,23	5,18	0,408
Norway	5,57	5,30	5,11	9,583***
Netherlands	5,45	5,28	5,15	5,600**
Belgium	5,14	4,86	4,73	8,783***
Switzerland	5,13	4,93	4,55	6,310**
France	5,17	4,99	4,85	5,043**
Germany	4,85	4,54	4,43	16,433***
Spain	5,27	5,08	4,88	3,739*
Cyprus	4,43	4,02	3,13	23,882***
Portugal	5,86	5,32	4,93	31,732***
Italy	5,06	4,69	3,83	7,893***
United Kingdom	4,84	4,80	4,63	1,674
Ireland	4,51	4,18	3,76	14,701***
Russian Fed.	4,50	4,03	3,93	19,489***
Ukraine	4,61	4,10	4,25	19,658***
Estonia	4,26	4,00	3,88	9,816***
Lithuania	4,29	3,42	2,90	83,992***
Albania	4,84	4,03	3,87	21,719***
Bulgaria	4,76	4,44	3,63	23,795***
Czech Republic	4,73	4,13	4,22	20,800***
Hungary	3,61	2,92	2,85	41,825***
Poland	4,24	3,75	3,53	22,893***
Slovenia	4,81	4,29	3,86	23,423***
Slovakia	4,81	4,53	4,14	8,547***

Source: ESS 2012. *=p<0.05 **=p<0.01 ***=p<0.001

2.4 Results

Model 1 shows that people with a chronic illness have significantly less informal social capital. Those who are hampered a lot (b=-0.647) have even less social capital than those who are hampered to some extent (b=- 0.374) as compared to healthy people. When we control for several individual level characteristics in Model 2, this relationship still holds (b=-0.186 and -0.407), confirming Hypothesis 1.

On the basis of Models 3–5, we can state that depression, subjective health, and perceived income in each model explain a large part of the initial relationship between chronic illness and informal social capital; all these mediators have the expected effects on chronic illness and, moreover, reduce the original differences in Models 1 and 2, respectively.

Table 2.4 (a). *Results multilevel analysis of the effect of chronic illness on informal social capital.*

	Model 1		**Model 2**		**Model 3**		**Model 4**		**Model 5**		**Model 6**	
	B	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**
Hampered by chronic illness (ref=no)												
• To some extent	-,374***	,038	-,186***	,032	-,076*	,030	-,036	,032	-,161***	,030	-,014	,030
• A lot	-,647***	,064	-,407***	,059	-,149*	,056	-,124*	,060	-,356***	,058	-,017	,056
Mediators												
Depression					-,436***	,014					-,366***	,015
Subjective health							,199***	,009			-,123***	,010
Perceived income (ref= comfortable)												
• Coping									-,110***	,019	-,077***	,019
• Difficult									-,274***	,024	-,178***	,024
• Very difficult									-,455***	,031	-,284***	,032
Control variables												
Gender (1=female)			-,017	,014	,023	,014	-,007	,014	-,013	,014	,024	,014
Age			-,015***	,001	-,015***	,001	-,013***	,001	-,016***	,001	-,014***	,001
Minority (1=yes)			-,083**	,029	-,044	,028	-,072*	,029	-,049	,029	-,023	,028
Education			-,002	,004	-,009*	,004	-,009*	,004	-,009*	,004	-,016***	,004
Income (ref=decile 1)												
• Decile 2			,042	,031	,009	,031	,031	,031	-,010	,031	-,024	,031
• Decile 3			,130***	,032	,063*	,032	,102**	,032	,042	,033	,003	,032
• Decile 4			,049	,033	-,028	,033	,019	,033	-,055	,033	-,098**	,033
• Decile 5			,071*	,034	-,013	,033	,035	,033	-,052	,034	-,097**	,034
• Decile 6			,118**	,034	,032	,034	,083*	,034	-,018	,035	-,060	,035
• Decile 7			,126***	,035	,034	,034	,085*	,035	-,026	,036	-,071*	,036
• Decile 8			,140***	,036	,041	,035	,089*	,036	-,027	,037	-,079*	,037
• Decile 9			,242***	,037	,139***	,037	,191***	,037	,061	,039	,010	,039
• Decile 10			,292***	,037	,180***	,037	,233***	,037	,092*	,040	,035	,039
• Missing			,169***	,029	,089**	,029	,134***	,029	,040	,030	-,001	,030
Having children (ref=no)												
• Yes at home			-,316***	,021	-,310***	,021	-,310***	,021	-,279***	,021	-,284***	,021
• Yes, not at home			,009	,024	,006	,024	,015	,024	,020	,024	,017	,024

Table 2.4 (a). *(continued)*

	Model 1		Model 2		Model 3		Model 4		Model 5		Model 6	
	B	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**
Marital status (ref=together with partner)												
1. Divorced/separated			,089***	,024	,135***	,024	,092***	,024	,111***	,024	,140***	,024
2. Widow(er)			,330***	,026	,397***	,026	,331***	,026	,327***	,026	,385***	,026
3. Never married			,341***	,023	,348***	,023	,335***	,023	,343***	,023	,345***	,023
Church attendance (ref=never)												
4. Less often			,069***	,019	,069***	,019	,069***	,019	,067***	,019	,068***	,019
• Only on specific holidays			,091***	,019	,085***	,019	,089***	,019	,056***	,019	,081***	,019
5. At least once a month			,076**	,025	,072**	,025	,072**	,025	,068**	,025	,066**	,025
6. Once a week			,165***	,026	,151***	,026	,156***	,026	,154***	,026	,141***	,025
• More than once a week/ every day			,294***	,039	,286***	,039	,286***	,039	,294***	,039	,283***	,039
Intercept	4,895***	,097	5,405***	,110	6,146***	,108	5,750***	,108	5,698***	,107	6,430***	,106
Variance individual level	2,308	,015	2,156	,014	2,115	,014	2,138	,014	2,146	,014	2,104	,014
Variance country level												
Intercept	,250	,068	,270	,074	,243	,067	,251	,069	,239	,065	,221	,060
Slope hampered by chronic illness: to some extent	,030	,011	,018	,007	,015	,006	,017	,007	,015	,006	,014	,006
Slope hampered by chronic illness: a lot	,078	,029	,065	,025	,057	,022	,055	,022	,062	,024	,053	,021
-2Loglikelihood	176918,902		172794,477		171858,061		172388,279		171364,415		171598,192	
N Individuals	47,543		47,543		47,543		47,543		47,543		47,543	
N Countries	27		27		27		27		27		27	

Source: ESS 2012

*= p<0.05; ** = p<0.01; *** = p<0.001.

***Table 2.4 (b)**. Results multilevel analysis of the effect of chronic illness on informal social capital.*

	Model 7		**Model 8**		**Model 9**		**Model 10**	
	B	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**
Hampered by chronic illness (ref = no)								
• To some extent	-,186***	,032	-,120*	,053	-,185***	,032	-,597***	,141
• A lot	-,407***	,059	-,263*	,104	-,407***	,058	-,875**	,282
Country level								
Health care expenditure					,203***	,044	,199***	,044
Welfare regimes (ref= Scandinavian)								
Anglosaxon	-,730*	,276	-,732*	,277				
Bismarkian	-,318	,218	-,319	,219				
Southern	-,259	,218	-,248	,219				
Former USSR	-1,060***	,218	-1,049***	,219				
Post communist	-,883***	,188	-,867***	,189				
Interactions								
Health care expenditure								
x to some extent							,047**	,016
x yes a lot							,053	,031
Welfare regimes								
Anglo-Saxon x to some extent			,092	,102				
Anglo-Saxon x a lot			,014	,197				
Bismarkian x to some extent			,038	,082				
Bismarkian x a lot			,057	,161				
Southern x to some extent			-,047	,091				
Southern x a lot			-,419*	,175				
Former USSR x to some extent			-,189*	,080				
Former USSR x a lot			-,139	,156				
Post communist x to some extent			-,166*	,073				
Post communist x a lot			-,300*	,142				
Control variables								
Gender (1=female)	-,017	,014	-,016	,014	-,017	,014	-,017	,014
Age	-,015***	,001	-,015***	,001	-,015***	,001	-,015***	,001
Minority (1=yes)	-,082**	,029	-,082**	,029	-,083**	,029	-,083**	,029
Education	-,002	,004	-,002	,004	-,002	,004	-,002	,004

Table 2.4 (b)*. (continued)*

	Model 7		**Model 8**		**Model 9**		**Model 10**	
	B	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**
Income (ref=decile 1)								
• Decile 2	,042	,031	,041	,031	,041	,031	,041	,031
• Decile 3	,129***	,032	,129***	,032	,129***	,032	,128***	,032
1. Decile 4	,048	,033	,049	,033	,048	,033	,047	,033
2. Decile 5	,070*	,033	,070*	,033	,070*	,033	,069*	,033
3. Decile 6	,118**	,034	,117**	,034	,117**	,034	,116**	,034
4. Decile 7	,125***	,035	,125***	,035	,124***	,035	,124***	,035
5. Decile 8	,139***	,036	,139***	,036	,139***	,036	,138***	,036
6. Decile 9	,241***	,037	,241***	,037	,241***	,037	,240***	,037
7. Decile 10	,291***	,037	,292***	,037	,291***	,037	,290***	,037
8. Missing	,169***	,029	,168***	,029	,168***	,029	,167***	,029
Having children (ref=no)								
• Yes at home	-,315***	,021	-,315***	,021	-,315***	,021	-,315***	,021
• Yes, not at home	,009	,024	,009	,024	,009	,024	,009	,024
Marital status (ref=together with partner)								
9. Divorced/separated	,089***	,024	,088***	,024	,089***	,024	,088***	,024
10. Widow(er)	,331***	,026	,333***	,026	,330***	,026	,331***	,026
11. Never married	,341***	,023	,341***	,023	,341***	,023	,341***	,023
Church attendance (ref=never)								
12. Less often	,069***	,019	,069***	,019	,069***	,019	,069***	,019
• Only on specific holidays	,091***	,019	,091***	,019	,091***	,019	,092***	,019
13. At least once a month	,076**	,025	,076**	,025	,076**	,025	,076**	,025
14. Once a week	,165***	,026	,164***	,026	,165***	,026	,165***	,026
• More than once a week/ every day	,294***	,039	,295***	,039	,294***	,039	,295***	,039
Intercept	5,931***	,146	5,922***	,146	3,619***	,396	3,653***	,397
Variance individual level	2,156	,014	2,156	,014	2,156	,014	2,156	,014
Variance country level								
Intercept	,112	,031	,113	,031	,150	,041	,151	,041
Slope hampered by chronic illness: to some extent	,018	,007	,008	,004	,018	,007	,012	,005
Slope hampered by chronic illness: a lot	,065	,025	,038	,017	,065	,024	,056	,022
-2Loglikelihood	172771,083		172748,999		172778,465		172768,640	
N Individuals	47,543		47,543		47,543		47,543	
N Countries	27		27		27		27	

Source: ESS 2012. *= p<0.05; ** = p<0.01; *** = p<0.001.

It is, moreover, interesting to note that Model 6 shows that the initial relationship in Model 1 is almost fully explained by depression, subjective general health, and perceived income. For people who are impeded to some extent in their daily activities, 92.5%[2] can be explained by a lack in these resources. For people who are impeded a lot in their daily activities, this is 95.8%[3]. We tested whether the mediations are significant, with the method of Preacher and Hayes (2008). Figure 2.1 presents the path diagram, in which it can be seen that all mediating effects are significant, hence supporting hypotheses 2, 3, and 4.

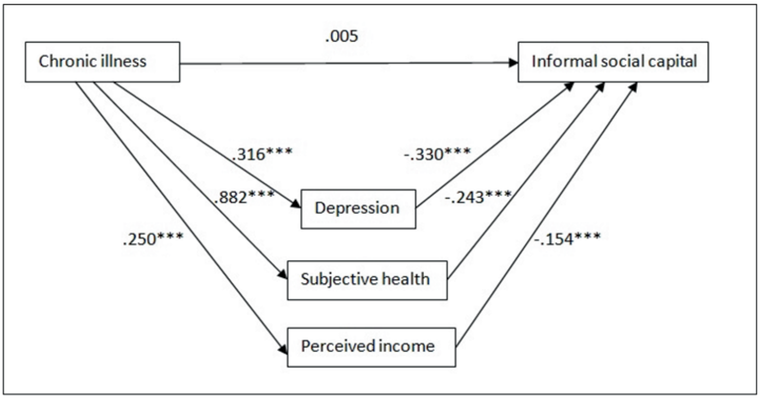

Figure 2.1. *Mediators for the original relationship between chronic illness and informal social capital.*
Source: ESS 2012

Regarding the country-level characteristics[4], Model 7 shows that there are differences in informal social capital between welfare regimes. People in Anglo-Saxon regimes have less informal social capital (b=-0.730) than people in Scandinavian countries. The Bismarkian and Southern regimes also differ, but not significantly from Scandinavian states in terms of the amount of informal social capital. Compared to the Scandinavian regime, post-communist and former USSR countries differ the most in the amount of

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[2] (-0.186) - (0.014)/-0.186 x 100 = 92.5%.

[3] (-0.407) - (-0.017)/-0.407 x 100 = 95.8%.

[4] We checked robustness of our results by controlling for log-transformed GDP per capita (ppp) in Models 7–10. Results showed a non-significant effect of GDP per capita (ppp) on informal social capital. Consequently, no substantial changes in our results were found.

informal social capital (b=-0.883 and -1.060). Thus, inhabitants of former USSR states differ most from the Scandinavians.

We expected that the relationship between chronic illness and informal social capital would be different in various welfare regimes. Model 8 shows that few interaction terms are significant. In post-communist regimes, the relationship between chronic illness and informal social capital is significantly negative (b=-0.867). For those who are hindered ‘to some extent’ and ‘a lot’, this relationship is even more negative (b =-0.166 and -0.300, respectively). As stated before, former USSR states have the least informal social capital (b=-1.049) of all welfare regimes. People who are only hampered ‘to some extent’ by their illness (b=-0.189) have even less social capital. The negative effect for people who are hampered ‘a lot’ is not significant (b=-0.139); however, the negative effect for those who are hampered ‘to some extent’ is significant (b=-0.189). Although Southern countries do not differ significantly from the Scandinavian regime in the amount of informal social capital (b=-0.248), people in these countries who are hampered ‘a lot’, do have significantly less informal social capital (b=-0.419). The other regimes do not differ significantly from Scandinavian countries in the relationship between chronic illness and informal social capital. Hypothesis 5 is thus only partly confirmed, particularly for the chronically ill in former USSR and post-communist countries[5].

Model 9 shows that people who live in countries that spend more on health care have more contact with friends, family and colleagues (b=-0.203). This can be seen in Model 10 as well (b=-0.199). Chronically ill people in countries that spend a lot on health care, have more informal social capital than these people in countries with a lower health-care expenditure, but this relationship is only significant for people who are hindered ‘to some extent’ by a chronic illness (b=-0.047) and not for people who are hampered ‘a lot’ (b=-0.053). Hence, we can conclude that Hypothesis 6 is partly confirmed as well.

Considering our control variables, Model 2 shows that the elderly, minority groups, people with children who live at home, and lower-income groups have less informal social capital. People who attend church regularly and people who are not together with a partner (divorced, never married,

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[5] Because relatively many variables were added in relation to the number of countries (Leyland & Groenewegen, 2020), we also carried out more parsimoneous analyses with a continuous measurement of decommodification (Israel & Spannagel, 2018) as a substantial substitute for the different welfare regimes. The main effect and interaction terms were in the expected direction and partly significant. Thus, no large substantial differences as compared to our original models were found.

and widowed) see friends, family and colleagues more often. This is consistent with prior research findings (Huijts, 2011; Lin, 2000; Van Oorschot et al., 2006; Savelkoul et al., 2011).

2.5 Discussion and conclusion

In this contribution we aimed to gain insight into the relationships between chronic illness and informal social capital. Research on this particular relationship is rather scarce, and hence we set out to fill this gap in our knowledge. We enriched existing knowledge by describing and explaining the relationship between chronic illness and informal social capital with individual and contextual level characteristics. We used representative and high-quality data on 27 European countries from the ESS (2012). Moreover, we applied multilevel regression analyses to test our hypotheses.

Previous research demonstrated that certain resources, such as income and education, have positive relationships with social capital (Berkman and Kawachi, 2000; Gesthuizen et al., 2008). Health can also be considered a resource fostering social capital. Our research showed that people who are hampered 'to some extent' by a chronic illness actually have less informal social capital than healthy people. Additionally, we found that people who are hampered 'a lot' have even fewer contacts with friends, family and colleagues. We found this pattern in most European countries. In line with our expectations, health is positively related to social capital, which could imply that health can be seen as a resource. We attempted to explain this relationship with several individual level mediators that indicate a lack of other resources, namely depression, subjective health, and perceived income. Results showed that these characteristics explained the initial relationship between chronic illness and informal social capital almost fully, when included simultaneously. These results support our reasonings that certain resources are important in explaining the relation between chronic illness and social capital.

Subsequently, we tested whether the initial relationship between chronic illness and social capital differed between European societies and how these differences could be explained. First of all, we found that, in accordance with our expectations, social capital differs across welfare regimes. Scandinavian countries seem to have the highest level of social capital, followed by Southern, Bismarkian, Anglo-Saxon, and post-

Communist countries. Social capital was lowest in former USSR countries. Only the difference between Scandinavian countries and Bismarkian, post-communist, and USSR countries was significant, thereby partly confirming our hypothesis on differences in social capital across welfare regimes. Subsequently, we proposed hypotheses about the moderating influence of welfare regimes; these findings provide innovative insights. We expected that welfare regimes differ in their ability to compensate for the lack of resources of the chronically ill. The findings suggest that post-communist and former USSR regimes compensate people with a chronic illness poorly to maintain informal social capital. As expected, people in this regime who suffer ('a lot') from a chronic illness, have even less social capital than the healthy people in these countries.

An interesting finding is that Southern countries also seem to compensate the chronically ill less than Scandinavian countries. However, only people who are hampered 'a lot' differ significantly from healthy people in their amount of informal social capital. In Southern European countries, there is a high degree of familialism (Trifiletti, 1999). We suspect that, when people are impeded to some extent, family members can still take care of their relatives. When the need for help becomes more severe, help from family may become insufficient. Thus, people who are hampered 'a lot' by their chronic illness in the Southern regime 'lose' more informal social capital.

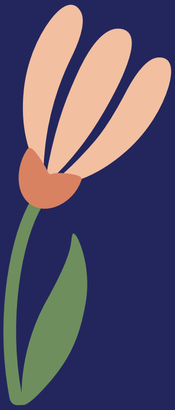
Regarding health-care expenditure, we found that the more countries spend on health care, the more informal social capital its inhabitants have. This relationship is even stronger for people who are hampered 'to some extent' by a chronic illness. This finding underlines the importance of taking into account health-care expenditure. For people who are hampered 'a lot', this effect does not reach significance. We suspect that for people who are hampered 'a lot', health limitations are so severe that health-care expenditure can no longer sufficiently compensate.

The theoretical framework of this study proposed a relationship between chronic illness and informal social capital. Yet, there are also studies that examined the positive and negative effects of social relations on health (Cohen, 2004; Kawachi et al., 1996).Hence, these studies proposed a reversed causal relationship in their theoretical framework. To the best of our knowledge, there are no studies that tested the direction of the relationship more thoroughly. Future research should improve on this by using panel data. It should be acknowledged that our measurement of social capital relies on one item only. Although this measurement has been used frequently in previous research and has been proven to be a valid indicator of informal social capital (e.g. Savelkoul et al., 2011), future research would benefit from a more comprehensive measurement in order to cover multiple aspects of informal social capital. Furthermore, it should be acknowledged that cross-national studies like ours can entail difficulties, such as problems concerning comparability or socio-cultural biases. Yet, our results on the relationship between chronic illness and social capital are robust. Differences in social capital between healthy and chronically ill people show the same pattern in every country (except Ukraine); healthy people have the highest level of social capital and people who are hampered ‘a lot’ by a chronic illness have the least social capital.

To answer our initial research questions, we found that the relationship between chronic illness and informal social capital can be mediated almost fully by depression, subjective health, and perceived income. Moreover, we showed that country characteristics play a role in this relationship. Countries differ in their ability to compensate for the lack of resources that affects people with chronic illness to continue their social contacts, as shown by significant moderators. The combination of explanatory individual characteristics and country-level features has thus been proven to be fruitful, and should be taken into account in future research.

CHAPTER 3

Differences in informal social capital and neighborhood participation between people with a chronic condition or impairment and the general population in the Netherlands



A slightly different version of this paper has been submitted to an international peer-reviewed journal.

Peer Scheepers, Ronald Batenburg, Alexander Haarmann and Anne Brabers are co-authors of this paper. Vis conducted the analyses and wrote the manuscript. Haarmann contributed with feedback on the analyses and on the manuscript. Scheepers, Batenburg and Brabers also substantially contributed to the manuscript.

Abstract

In the Netherlands, the Social Support Act defines that municipalities are responsible for parts of the care of people with a chronic condition or physical impairment. The assumption behind this act is that municipalities know best how people can strive for societal participation and rely on their own network as much as possible. This study investigates differences in informal social capital and neighborhood participation between people with a chronic condition and/or physical impairment and the general population in the Netherlands – including factors on the individual and municipality level that may play a role in this relationship. We used data from two panel surveys and public government data on the political characteristics of municipalities and carried out multilevel analyses. We found significant lower levels of informal social capital and neighborhood participation of people with a chronic condition and/or a severe impairment, compared to the general population. People with a moderate impairment also participate significantly less in their neighborhood compared to the general population. On the relationship between the level of impairment on the one hand, and informal social capital and neighborhood participation on the other, depression has the most important mediating effect. Political characteristics of the municipalities individuals live in (measured by a constructed Social Support Policy Index), did not have significant effects on the relationship between the level of impairment and neighborhood participation. For people who are severely impaired however, we found a significant and positive interaction effect: for this group, living in municipalities with more progressive policies on social support, has relatively more informal social capital. This research shows that significant differences exist in informal social capital and neighborhood participation between people with a chronic condition and/or physical impairment and the general population in the Netherlands. There are small differences between municipalities, but for people with a severe impairment, local social policies positively influence their social capital and neighborhood participation, which subsequently can enhance self-reliance.

3.1 Introduction

Several studies have been published on the relationship between having a chronic condition, or physical impairment, and social capital (Haas et al., 2018, Oldenkamp et al., 2018, Vis et al., 2018, Rodgers et al., 2019). Most of these studies showed that having a chronic condition and informal social capital is negatively related. Still, the mediating and moderating mechanisms at the individual and contextual level behind this relationship have been researched less often. We can refer to two examples of studies that investigated the *moderating* influence of (national or regional) policies on the relationship between chronic condition and social capital. One study found that the strength of this relationship varies between European countries (Vis et al., 2018): countries with social democratic regimes were more successful to help chronically ill maintain their social capital than other countries (Vis et al., 2018). In a second study, Waverijn et al. researched the effect of 'neighborhood social capital' on the provision of local services and amenities in Dutch municipalities. The hypothesis that these local services could work as a supporting mechanism between social capital and health, found little conclusive evidence (Waverijn et al., 2017).

The Netherlands is an interesting country to research these topics for a number of reasons. Part of the long term support and care for chronically ill in the Netherlands has been transferred to municipalities by the Social Support Acts of 2007 and 2015, including (mental health) care services, day care and support care (Kroneman et al., 2016). Municipalities receive state subsidies, based on uniform criteria but independent from actual spending levels, and are able to define their own policies. Differences between municipalities in terms of budgets depend on the socio-demographic profile of their inhabitants, but this does not explain all variation between municipalities (Ooms et al., 2017). To strengthen societal participation (including social capital) is also an important starting point of the Social Support Act. The idea of the Act is that municipalities first look at the self-reliance of people and their social network and only offer help when this is insufficient (Kroneman et al., 2016). Moreover, the policy of municipalities is to enable people to keep living at home, promote mobility and encourage people to engage in social contacts (for example in community centers). The critical role that social capital is assumed to play in the Dutch Social Support Act, and the possible variation between municipalities within the Netherlands regarding how they actually execute this Act, provide two important contextual reasons to use Dutch data to deepen the knowledge about the relationships between having a chronic condition and/or physical impairment, social capital and neighborhood participation.

In this paper, we will research to what extent people with a chronic condition and/or physical impairment differ from the general population in terms of social capital and neighborhood participation. We will also look into individual level and contextual level characteristics that may play a role in this relationship.

The concept of social capital has a strong theoretical foundation in literature (Bourdieu, 1986, Putnam, 2000, Pichler & Wallace, 2007). To attain social capital, it is theorized that individuals need resources to invest in these relationships, such as monetary resources (income) or non-monetary resources (knowledge or preferences) (e.g. Tigges et al., 1998). Haas et al. (2010) proposed that poor health can reduce the time and energy to maintain social relationships. We thus theorize that health can be seen as a resource that is helpful in maintaining social capital (Hogan et al., 1993) and vice versa, a lack of health (i.e. having a chronic condition or impairment) can impose restrictions when it comes to maintaining social capital. Since literature shows that there are resources such as income (Tigges et al., 1998) can play a role as well in the attainment of social capital, we will also examine whether people’s ability to make ends meet (‘subjective income’), is also a resource that can be invested in social capital. Hence, subjective income might explain the expected negative relationship between chronic condition and informal social capital, as well as neighborhood participation. Also, research has shown that physical and mental health are strongly related (Birk et al., 2019, Portela et al., 2013) and that subjective health is related to several forms of social capital (Portela et al., 2013), so we will next to subjective health and psychological health.

To research whether contextual characteristics play a role in the relationship between having a chronic condition or disability and social capital, we build on research that explored why some countries have more or less differences in informal social capital between people who are hampered by a chronic condition and people who are not (Vis et al., 2018). The idea is that some countries are able to compensate people with a chronic condition or physical impairment better for a loss of resources that are needed for the attainment of social capital (Vis et al., 2018). This idea is based on prior research (Esping-Andersen, 1990, Trifiletti, 1999, Fenger, 2007, Bambra & Eikemo, 2008), that classified welfare regimes based on their level of 'decommodification'. Decommodification refers to the extent to which individuals' welfare relies on the market (Eikemo et al., 2008). Like countries, Dutch political parties at the national and municipality level can be categorized as parties that promote higher or lower levels of decommodification, and thus mirror the descriptions of ideologies of welfare states as described by this prior research.

At the time of this study there were the following parties that can be classified. The Socialist Party (SP), the Labour Party (PvdA), and Green Left (GroenLinks) can be identified as parties who prefer redistribution of income to the greatest extent. They best fit the description of social-democratic regimes (Esping-Andersen, 1990). The Christian Union (Christen Unie), Christian Democratic Appeal (CDA) and the Reformed Political Party (SGP) are parties with a Christian identity. Redistribution of income is less far-reaching than preferred by social-democratic parties. These parties fit best into descriptions of conservative corporatist regimes (Esping-Andersen, 1990, Bambra & Eikemo, 2008). The People's Party for Freedom and Democracy (VVD) and Democrats 66 (D66) identify themselves as liberal parties. Their policies focus on a reliance on the market and prefer the least of all the parties to redistribute income into social security policies. These parties fit best into the description of liberal regimes (Esping-Andersen, 1990). There are also local parties active on the municipality level, that gained popularity in the last 20 years. These local parties were mostly initiated pragmatically, not following the ideologies that are present in national politics, but explicitly connecting to the local needs of citizens in the municipality leaving behind traditional left-right distinctions (Janssen & Korsten, 2003, Boogers et al., 2007). This political variety makes it relevant to investigate whether municipalities with more councilors of parties that have a greater focus on decommodification, 'compensate' chronically ill individuals more in their social capital and neighborhood participation.

The expectations tested in this paper are based on above notions and (merely) formulated to give guidance to our analyses in an as concise manner as possible. The research questions that will be addressed in this paper are as follows:

(1) What are the differences between people with a chronic condition and the general population, in terms of informal social capital and neighborhood participation in the Netherlands?

(2) *To what extent is the relationship between having a chronic condition on the one hand, and informal social capital as well as neighborhood participation on the other, (a) mediated by individual level characteristics and (b) moderated by characteristics on the municipality level?*

3.2 Data and methods

3.2.1 Data

This study used data collected within the Dutch Participation monitor in 2017 carried out by the Netherlands Institute for Health Services Research (Nivel). This monitor measures participation among both the general population and persons with a chronic condition or disability. Data are collected using surveys from two panels: the National Panel of people with Chronic condition or Disabilities (NPCD) and the Dutch Healthcare Consumer Panel (DHCP). Protection of the data was in 2017 registered with the Dutch Data Protection Authority (NPCD: 1283171; DHCP: 1262949). Data are processed pseudonomised and handled in accordance with the privacy protection guidelines of the Dutch Data Protection Authority. For both panels, privacy regulations apply. According to Dutch legislation, obtaining informed consent or approval by a medical ethics committee, is not mandatory for carrying out research in this panel.

The NPCD consists of around 4,000 people of 15 years or older, live independently and have a (medically diagnosed) illness or physical disability. Members of the panel are recruited via general practitioners and Statistics Netherlands[1]. The aim of the panel is to gather information about the consequences of living with a chronic condition or disability. Panel members receive questionnaires twice a year (Van Hees et al., 2018, Nivel, 2020).

The DHCP consists of almost 12,000 members of 18 years or older at the moment of the study (here: October 2017). Members are recruited in two ways: (1) by random selection from address files purchased from a national address supplier and (2) via general practices that are included in the Nivel from the Primary Care Database[2]. The aim of this panel is to

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[1] Some members are also recruited via other research projects (e.g. Use of Facilitiesresearch (SCP, 2007), WoOn-researhc (Ministry of the Interior and Kingdom Relations; SCP (2009; 2012), but these are not included in this research.

[2] For more information, see: https://nivel.nl/en/nivel-primary-care-database

measure: (1) opinions on healthcare, (2) knowledge about healthcare, (3) experiences with healthcare and (4) expectations of healthcare. Panel members receive about three questionnaires per year (Brabers et al., 2015, Brabers, 2018, Nivel 2020).

Municipality characteristics were measured by publicly available data on the website of the government (https//data.overheid.nl), including the political party composition of all the Dutch municipality councils. The publication of these data is commissioned by the Ministry of Interior and Kingdom Relations and contains (amongst other things) information about all councilors per municipality, including their political party. We used the available data for the year 2017.

Data from the different sources mentioned above were appended to one integrative dataset. For this dataset, we excluded respondents with missing values on individual level variables. Also, we excluded respondents from municipalities with only 1 or 2 respondents (Snijders & Bosker, 2012) in order to test our individual level hypotheses. The remaining dataset consisted of 2,283 individuals living in 233 municipalities, which covers approximately 60% of all municipalities in the Netherlands in 2017. To test our cross-level interaction hypothesis, we made a second subselection of municipalities with at least 15 respondents from the original data (Snijders & Bosker, 2012), which resulted in a dataset of 48 municipalities and 1,289 individuals.

3.2.2 Measurement of informal social capital and neighborhood participation

Informal social capital was measured by the question “How often do you socially meet with (1) (grand)children, (2) relatives, (3) friends, (4) neighbors” Answering categories were: at least once a week, twice a month, once a month, less than once a month, (almost) never and not applicable. People who did not have (grand)children, relatives, friends or neighbors and thus stated the item was not applicable were categorized into the category never. A factor analysis proved that a scale with one dimension was most suitable but Cronbach’s alpha value appeared to be 0.47. Deleting one or more items from the scale did not improve reliability. While according to prior studies (De Heus et al., 1995) a Cronbach’s alpha of at least 0.60 is considered eligible we chose to continue our analysis with this scale, since prior research has used the same measurement (Savelkoul et al., 2011) and the scale fits our theoretical framework best (i.e. taking into account the social network as a whole).

To measure neighborhood participation we used the question “How often do you (1) visit neighbors socially, (2) go outside with neighbors, like walking or going somewhere, (3) help neighbors, for example with getting groceries”. Answering categories were at least once a week, at least once a month, less than once a month and (almost) never. A factor analysis and reliability check showed that these items form a reliable scale by a Cronbach’s alpha of 0.65.

3.2.3 Measurement of chronic condition (level of impairment)

Participants of the NPCD are officially diagnosed with a chronic condition or disability. Their level of impairment is based on 27 items[3] about physical limitations. The same method is used by The Netherlands Institute for Social Research (de Klerk et al, 2006). The DHCP consists of a representative sample of the Dutch population. For these panel members, it is not known whether participants are diagnosed with a chronic condition or disability by a healthcare professional. Therefore all members of the DHCP panel are included in the analysis as the first category of our independent variable, i.e. the reference group. Next, four categories of respondents from the NPCD were constructed: (1) having a chronic condition but no impairment, (2) having a chronic condition and/or a mild impairment, (3) having a chronic condition and/or a moderate impairment, and (4) having a chronic condition and/or a severe impairment. Of 229 people (10%) of the NPCD panel, it is unknown whether they have a chronic condition, but it was known that they have a mild, moderate or severe impairment. This group was included in the analysis assuming that they have a chronic condition as they are participants of the NPCD.

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[3] Standing 10 minutes, sitting 10 minutes, 30 minutes standing/sitting, getting up or sitting down, getting in and out of bed, getting dressed/putting on shoes, climbing the stairs, entering or leaving a house, getting around out of the house, washing hands and face, washing my whole body, using the toilet, walk for 10 minutes without a break, daily groceries, preparing a hot meal, change bedding, doing laundry, using kitchen stairs, light domestic chores (dusting, doing the dishes), heavy domestic chores (mopping, cleaning windows), small repairs around the house (answering categories: *I can do this without problems, I can do this with effort, I cannot do this)* problems with eyesight, problems hearing (answering categories: *good/moderate/bad*).

3.2.4 Measurement of subjective health, subjective income and feelings of depression/anxiety

Subjective health was measured by the question *"We would like to know how good or bad your health is today"*. People could rank their health on a scale from 0 to 100. This measurement was used in several studies as an indicator of health (Eikemo, 2010).

To measure subjective income, respondents were asked *"How would you describe your financial situation?"*. Answer categories were *I need to make debts, I need to use my/our savings, I make ends meet, I can save a little money* and *I can save a lot of money.* Similar questions are used in for example the European Social Survey and other research (Visser et al., 2014).

Concerning mental health, respondents were asked about feelings of anxiety or depression. People made an estimation on the following 5-point scale: *I am not anxious or depressed, I am a little anxious or depressed, I am moderately anxious or depressed, I am very anxious or depressed* and *I am extremely anxious or depressed.*

3.2.5 Measurement of municipality characteristics: Social Support Policy index

For each municipality it was determined how many councilors represented a local party, a social-democratic party, a corporatist party and a liberal party, in 2017. To calculate an index-measurement of these combinations we used the following formula:

$$\frac{\begin{gathered}((\textit{N councilors of a local party} * 4) + (\textit{ N councilors of a social democratic party} * 3) + \\ (\textit{N councilors of a corporatist oarty} * 2) + (\textit{Ncouncilors of a liberal party} * 1))\end{gathered}}{\textit{N councilors in the municipality}}$$

Since we assume that local parties will be able to compensate chronically ill the most, because they aim their party's program specifically on local needs, we decided to assign a score of 4 points to these councilors, followed by councilors of a social-democratic party (3 points), and councilors of a corporatist party (2 points). We also expect the lowest level of decommodification in liberal parties, so we assigned them a score of 1. We coin this index as the 'Social Support Policy Index' (SSPI). A higher score on this index means that we expect a higher level of decommodification in municipalities. The SSPI should be seen as a proxy of the decommodification policy that Dutch municipalities carried out in 2017. While it is not a 'precise' and direct measurement of this municipality policy, it is based on prior research on characteristics of political parties/systems (Esping-Andersen, 1990, Janssen & Korsten, 2003, Boogers et al., 2007, Vis et al., 2018).

3.2.6 Measurement of the control variables

We controlled for church attendance (Huijts & Kraaijkamp, 2011), level of education (Cutler & Lleras-Muney, 2006), age and gender (Gray, 2009, Huijts, 2011), income (Berkman & Kawachi, 2000), household composition (Putnam, 2000, Gray, 2009, Lindström, 2009, Lin, 2000) and if respondents belonged to a minority group in the Netherlands (Lin, 2000). These control variables are based on the cited research and literature, showing that they correlate with measurements of social capital.

Church attendance was measured by the question *"How often do you attend a religious meeting?" (At least once a week, at least once a month, less than once a month, (almost) never).* This variable was coded so that a higher score means a higher church attendance. Level of education was categorized in three categories: *low* (up to LBO (primary vocational education)), *medium* and *high* (HBO/university). Age was categorized in: 15 to 39 years old, 40 to 64 years old, 65 to 75 years old and 75 years and older. Income was measured by the question *"Can you indicate your household's income after taxes in 2016 (last year)?"* The categories were divided in above or below average (€2,100) corresponding as much as possible with calculations of the Netherlands Bureau for Economic Policy Analysis over 2016 (CPB, 2016). It was not possible to distinguish the data into more detailed categories because of small differences in measurement between the NPCD and DHCP. Furthermore we controlled for gender (1=female), household composition (1=multi-person household) and minority (1=yes).

Table 3.1 shows descriptive statistics of all variables included in the analyses. Table 3.1 is based on the sample used for testing individual level hypotheses. Comparing descriptive statistics with the smaller samples used to test the cross-level interaction hypotheses shows that these samples are much alike in terms of our dependent variables as well as in terms of demographic characteristics. The smaller sample only shows a relatively smaller group of the general population versus chronically ill (40%) (results not shown).

3.2.7 Strategies for analyses

We used random intercept multilevel regression analyses. Chi-square tests showed that for informal social capital, a multilevel model has a significantly better fit than a linear regression model. This was not the case for neighborhood participation, but because of the nested nature of the data, we found that multilevel analyses were best suited for both dependent variables. Intraclass correlations of 2% (informal social capital) and 1% (neighborhood participation) were found, showing that just a small percentage of variance can be explained by municipality characteristics. Although we found low level 2 variances, we tested our hypothesis on the municipality level. We will test the following hypotheses:

Informal social capital	**Neighborhood participation**
(1a) The more people are impaired (by a chronic condition), the less informal social capital they will have compared to the general population.	(1b) The more people are impaired (by a chronic condition), the less they will participate in the neighborhood compared to the general population.
(2a) The negative relationship between chronic condition/impairment and informal social capital is mediated by subjective health.	(2b) The negative relationship between chronic condition/impairment and neighborhood participation is mediated by subjective health.
(3a) The negative relationship between chronic condition/impairment and informal social capital is mediated by feelings of depression or anxiety.	(3b) The negative relationship between chronic condition/impairment and neighborhood participation is mediated by feelings of depression or anxiety.
(4a) The negative relationship between chronic condition/impairment and informal social capital is mediated by subjective income.	(4b) The negative relationship between chronic condition/impairment and neighborhood participation is mediated by subjective income.
(5a) The differences in informal social capital between people who are impaired (by a chronic condition) and the general population will be smaller in municipalities with more councilors of parties that promote decommodification, compared to municipalities with more councilors of parties that promote decommodification to a lesser extent.	(5b) The differences in neighborhood participation between people who are impaired (by a chronic condition) and the general population will be smaller in municipalities with more councilors of parties that promote decommodification, compared to municipalities with more councilors of parties that promote decommodification to a lesser extent.

Table 3.1. *Descriptive statistics of all variables included in the analysis of individual level hypotheses.*

	N	% in category 1	Min	Max	Mean	S.D.
Continuous variables						
Informal social capital	2283	-	1	5	3.63	0.91
Neighborhood participation	2283	-	1	4	1.63	0.73
Subjective health	2283	-	5	100	74.53	17.60
Anxiety/depression	2283	-	1	5	1.34	0.67
Subjective income	2283	-	1	5	3.49	0.93
Church attendance	2283	-	1	4	1.52	1.03
Level of education	2283	-	1	3	2.09	0.73
Social support policy index	2283	-	1.25	4	2.38	0.50
Categorical variables						
Chronic condition (level of impairment)						
- general population	1214	53.2				
- chronic condition but no impairment	255	11.2				
- mild impairment	268	11.7				
- moderate impairment	391	17.1				
- severe impairment	155	6.8				
Age						
15 – 40	157	6.9				
40 – 65	783	34.3				
65 – 75	742	32.5				
75 +	601	26.3				
Income						
- Below average	1032	45.2				
- Above average	1251	54.8				
Gender						
- Male	1115	48.8				
- Female	1168	51.2				
Household composition						
- Single-person household	719	31.5				
- Multi-person household	1564	68.5				
Minority						
- No	2098	91.9				
- Yes	185	8.1				

For both informal social capital and neighborhood participation, the first model only includes our main independent variable, chronic condition including their levels of impairment. The second model takes into account our control variables, to see whether main effects still hold (hypothesis 1a and 1b). Model 3 to 5 test the mediating hypotheses (2a/b to 4a/b) by adding the mediators separately in each model. After that, we added all mediating variables in model 6 simultaneously. Random intercept and fixed slopes were estimated. Model 7-9 test our interaction hypotheses on the municipality level (hypothesis 5a/b) so random instead of fixed slopes were estimated. First the main effect of the presence of different political parties in the municipalities was tested in model 7. In model 8 the interaction effects were added and model 9 includes all variables on the individual and municipality level to check the robustness of our findings. To test our mediation hypotheses (2a/b to 5a/b) we carried out mediation analyses (Hayes, 2014). Although this method is based on linear OLS regression, we propose that it provides valuable insights, mainly because low level 2 variances were found. As could be expected, little differences were found between the estimates of the mediation analyses and multilevel analyses, supporting the proposition that in this case mediation analyses are suitable to use. Furthermore, all mediators showed significant relationships in the expected direction with our independent variable for the categories *moderate* and *severe impairment*. The analyses were conducted with use of Stata and SPSS (regression analyses and mediation analysis).

3.3 Results

3.3.1 Results on informal social capital

The results concerning informal social capital as the dependent variable are shown in table 3.2 and 3.3. Model 1 shows that compared to the 'general population' (i.e. the DHCP members), individuals who have a chronic condition but no impairment have more informal social capital (b=0.228). People who are impaired severely have the least informal social capital (b=–0.297). These effects hold after adding the control variables in model 2. Thus, hypothesis 1a expecting that the more people are impaired, the less informal social capital they have is partly confirmed. The hypothesis only holds for people who are impaired severely and not for those who have a mild or moderate impairment.

Model 3 first shows that the better subjective health is, the more informal social capital people have (b=0.005). The original relationship between being impaired and/or having a chronic condition and informal social capital is lowered by this intermediation, by 1%[4] (chronic condition but no impairment) up to 39% (impaired severely)[5].

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[4] $\frac{(0.180-0.178)}{0.180} * 100 = 1\%$

[5] $\frac{(-0.305--0.186)}{-0.305} * 100 = 39\%$

Table 3.2. *Results multilevel analysis of the effect of chronic condition on informal social capital.*

	Model 1		**Model 2**		**Model 3**		**Model 4**		**Model 5**		**Model 6**	
	B	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**
Chronic condition (ref=general population)												
- chronic condition but no impairment	0.228***	0.065	0.180**	0.063	0.178**	0.063	0.161*	0.063	0.183**	0.063	0.163**	0.063
- mild impairment	0.068	0.062	0.044	0.061	0.072	0.061	0.046	0.060	0.046	0.061	0.063	0.060
- moderate impairment	-0.079	0.053	-0.098	0.053	-0.019	0.055	-0.058	0.053	-0.088	0.053	-0.013	0.055
- severe impairment	-0.297***	0.077	-0.305***	0.077	-0.186*	0.081	-0.241**	0.077	-0.285***	0.078	-0.171*	0.081
Mediators												
Subjective health					0.005***	0.001					0.003**	0.001
Depression							-0.192***	0.001			-0.165***	0.030
Perceived income									0.040	0.022	0.012	0.022
Control variables												
Gender (ref=male)			0.202***	0.039	0.209***	0.038	0.214***	0.038	0.202***	0.039	0.217***	0.038
Minority (ref=no)			-0.032	0.068	-0.032	0.068	-0.038	0.067	-0.028	0.068	-0.036	0.067
Household composition (ref=single-person household)			0.301***	0.046	0.290***	0.046	0.292***	0.046	0.303***	0.046	0.287***	0.046
Income (ref=below average)			0.123**	0.045	0.106*	0.045	0.103*	0.045	0.097*	0.047	0.087	0.047
Age (ref=15-40 years)												
- 40-65 years			0.050	0.079	0.052	0.079	0.025	0.078	0.065	0.079	0.035	0.079
- 65-75 years			0.213**	0.079	0.203*	0.079	0.166*	0.079	0.221**	0.079	0.168*	0.079
- 75 or older			0.171*	0.082	0.171*	0.082	0.120	0.082	0.180*	0.082	0.130	0.082
Level of education			-0.023	0.028	-0.033	0.028	-0.031	0.028	-0.026	0.028	-0.038	0.028
Church attendance			0.073***	0.018	0.071***	0.018	0.069***	0.018	0.074***	0.018	0.068***	0.018
Intercept	3.632***	0.028	3.072***	0.108	2.680***	0.136	3.394***	0.117	2.938***	0.131	3.069***	0.173
Variance individual level	0.809	0.025	0.772	0.024	0.766	0.023	0.757	0.023	0.771	0.023	0.755	0.023
Variance municipality level:												
Intercept	0.012	0.008	0.007	0.007	0.006	0.006	0.006	0.006	0.008	0.007	0.006	0.006
-2Log likelihood	6025		5908		5886		5862		5904		5854	
N individuals	2283		2283		2283		2283		2283		2283	
N municipalities	233		233		233		233		233		233	

Source: Nivel 2018. Fixed slope, random intercept.
*p<0.05; **p<0.01; ***p<0.001.

***Table 3.3**. Results multilevel analysis of the effect of chronic condition on informal social capital.*

	Model 7		**Model 8**		**Model 9**	
	B	**S.E.**	**B**	**S.E.**	**B**	**S.E.**
Chronic condition (ref=general population)						
- chronic condition but no impairment	0.161*	0.072	0.329	0.338	0.383	0.334
- mild impairment	0.041	0.085	0.333	0.412	0.386	0.405
- moderate impairment	-0.096	0.069	0.058	0.341	0.094	0.337
- severe impairment	-0.321**	0.108	-1.378**	0.488	-1.130*	0.486
Mediators						
Subjective health					0.004*	0.002
Depression					-0.148***	0.040
Perceived income					0.029	0.030
Moderators						
Social support policies	0.002	0.056	0.012	0.086	0.015	0.085
Social support policies						
x chronic condition but no impairment			-0.073	0.144	-0.105	0.142
x mild impairment			-0.122	0.172	-0.136	0.169
x moderate impairment			-0.067	0.146	-0.049	0.144
x severe impairment			0.455*	0.207	0.413*	0.204
Control variables						
Gender (ref=male)	0.172***	0.051	0.175***	0.051	0.194***	0.051
Minority (ref=no)	0.018	0.086	0.021	0.086	0.007	0.085
Household composition (ref=single-person household)	0.328***	0.060	0.327***	0.060	0.318***	0.059
Income (ref=below average)	0.114	0.059	0.121 *	0.059	0.070	0.062
Age (ref=15-40 years)						
- 40-65 years	0.089	0.109	0.088	0.109	0.094	0.108
- 65-75 years	0.282*	0.109	0.281*	0.109	0.253*	0.109
- 75 or older	0.178	0.113	0.173	0.113	0.145	0.113
Level of education	-0.030	0.036	-0.031	0.036	-0.040	0.036
Church attendance	0.077**	0.025	0.077**	0.025	0.075**	0.025
Intercept	3.027***	0.196	3.005***	0.243	2.870***	0.305
Variance individual level	0.758	0.031	0.755	0.031	0.739	0.030
Variance municipality level:						
Intercept	0.004	0.007	0.004	0.007	0.003	0.006
Slope chronic condition:						
- chronic condition but no impairment	.000	0.000	.000	0.000	.000	0.000
- mild impairment	0.041	0.046	0.036	0.045	0.033	0.042
- moderate impairment	.000	0.000	.000	0.000	.000	0.000
- severe impairment	0.011	0.068	.000	0.000	.000	0.000
-2Log likelihood	3317.828		3310.722		3281.543	
N individuals	1289		1289		1289	
N municipalities	48		48		48	

Source: Nivel 2018. Random slope, random intercept. *p<0.05; **p<0.01; ***p<0.001.

Subsequently, model 4 shows a similar effect for of depression or anxiety, which lowers the effects on informal social capital as well. The main effect of depression on informal social capital is significant (b=−0.192), while depression decreases the relationship between being impaired and/or having a chronic condition and informal social capital with 11% (chronic condition but no impairment)[6] and 21% (impaired severely[7]). Model 5 shows the effect of perceived income, which is also in the expected direction (coping easier on one's income is positively related to informal social capital) but not significant (b=0.040). Lastly, model 6 shows that when the three mediators are added simultaneously, subjective health and depression or anxiety keep their significant effect on informal social capital. Both mediators also weaken the main relation between informal social capital and having a chronic condition but no impairment (b=0.180 versus b=0.163), and of being severely impaired (b=−0.305 versus b=−0.171).

Additional mediation analyses show that the mediation effect of both subjective health and depression are significant (see Appendix B). This means we can accept hypothesis 2a and 3a, which expected that the negative relationship between having a chronic condition or physical impairment and informal social capital, is mediated by a lower subjective health and feelings of depression. Hypothesis 4a, which expects that the main relationship between suffering from a chronic condition and informal social capital is mediated by a lower subjective income, however, is not confirmed.

Model 7 to 9 include the effect of municipality political characteristics as measured by the SSPI. Model 7 shows that SSPI has no significant effect on informal social capital. Of all interaction effects in model 8, one is significant: for people who are impaired severely, the effect between impairment and informal social capital is positive and significant (b=0.455). This implies that in municipalities with a higher SSPI, individuals have more informal social capital and for individuals with a chronic condition that are severely impaired, this relationship is significantly stronger. We partly accept hypothesis 5a as only one interaction effect appeared to be significant.

Finally, we conclude that all confirmed hypotheses hold their significant effect and thus remain supported when control variables are added that are known to influence social capital; showing that these results are robust.

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[6] $\frac{(0.180-0.161)}{0.180} * 100 = 11\%$

[7] $\frac{(-0.241--0.305)}{-0.305} * 100 = 21\%$

3.3.2 Results on neighborhood participation

The results concerning neighborhood participation as the dependent variable are shown in table 3.4 and 3.5. It appears that people who are impaired participate less in their neighborhood than the general population. For people with a moderate or severe impairment, these effects are significant (b=−0.092 and b=−0.230 respectively). These effects hold when control variables are added, which means that hypothesis 1b, which expected that people who are to some extent impaired and have a chronic condition would participate less than the general population, is partly be confirmed (only for people with a moderate or severe impairment).

Model 3 shows that having a better subjective health has a small positive effect on neighborhood participation (b=0.002). In addition, when subjective health is added to the model, the initial relationship between having a chronic condition or impairment and neighborhood participation is reduced by 26%[8] (in case of moderate impairment) and 18%[9] (for the severe impairment subgroup). This implies that hypothesis 2b is accepted, however, in model 6 where all mediators are added simultaneously, this relationship is no longer significant, just as in the mediation analysis (see Appendix B). Therefore hypothesis 2b is not confirmed. Model 4 shows the negative relationship between feelings of anxiety or depression and neighborhood participation (b=−0.077). Adding this mediator to the model also reduces the relationship between being impaired by a chronic condition, namely by 13%[10] (moderate impairment) and 10%[11] (severe impairment). When we look at model 6, with all mediators added, and at the mediation analysis (see Appendix B), the relationship remains significant. Hypothesis 3b is therefore accepted. Model 5 shows that the relationship between perceived income and neighborhood participation (b=0.013) is not significant. Hypothesis (4b) expected that perceived income would also mediate the initial negative relationship between chronic condition and/or physical impairment and neighborhood participation, is therefore not accepted.

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[8] $\frac{(-0.123--0.091)}{0.123} * 100 = 26\%$

[9] $\frac{(-0.273--0.224)}{-0.273} * 100 = 18\%$

[10] $\frac{(-0.123--0.107)}{-0.123} * 100 = 13\%$

[11] $\frac{(-0.273--0.247)}{-0.273} * 100 = 10\%$

***Table 3.4**. Results multilevel analysis of the effect of chronic condition on neighbourhood participation.*

	Model 1		Model 2		Model 3		Model 4		Model 5		Model 6	
	B	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**
Chronic condition (ref=general population)												
- chronic condition but no impairment	0.013	0.051	0.013	0.050	0.011	0.050	0.005	0.050	0.014	0.050	0.005	0.050
- mild impairment	-0.029	0.049	-0.049	0.049	-0.038	0.049	-0.048	0.049	-0.048	0.049	-0.041	0.049
- moderate impairment	-0.092*	0.042	-0.123**	0.043	-0.091*	0.045	-0.107*	0.043	-0.119**	0.043	-0.089*	0.045
- severe impairment	-0.230***	0.062	-0.273***	0.062	-0.224***	0.065	-0.247***	0.062	-0.266***	0.063	-0.219***	0.065
Mediators												
Subjective health					0.002*	0.001					0.001	0.001
Depression							-0.077***	0.001			-0.066**	0.024
Perceived income									0.013	0.018	0.002	0.018
Control variables												
Gender (ref=male)			0.153***	0.031	0.155***	0.031	0.158***	0.031	0.152***	0.031	0.159***	0.031
Minority (ref=no)			-0.015	0.055	-0.015	0.055	-0.017	0.055	-0.014	0.055	-0.017	0.055
Household composition (ref=single-person household)			-0.026	0.037	-0.031	0.037	-0.029	0.037	-0.025	0.037	-0.032	0.037
Income (ref=below average)			0.015	0.036	0.008	0.036	0.007	0.036	0.006	0.038	0.002	0.038
Age (ref=15-40 years)												
- 40-65 years			0.171**	0.064	0.172**	0.063	0.161*	0.063	0.176**	0.064	0.164*	0.064
- 65-75 years			0.321***	0.064	0.317***	0.064	0.302***	0.064	0.323***	0.064	0.302***	0.064
- 75 or older			0.312***	0.066	0.312***	0.066	0.292***	0.066	0.315***	0.066	0.295***	0.067
Level of education			0.030	0.022	0.026	0.023	0.027	0.022	0.029	0.023	0.024	0.023
Church attendance			0.045**	0.015	0.045**	0.015	0.044**	0.015	0.046**	0.015	0.043**	0.015
Intercept	1.660***	0.021	1.225***	0.087	1.066***	0.110	1.354***	0.095	1.181***	0.105	1.230***	0.140
Variance individual level	0.519	0.016	0.504	0.015	0.503	0.015	0.502	0.015	0.504	0.015	0.501	0.015
Variance municipality level:												
Intercept	0.004	0.004	0.001	0.004	0.001	0.004	0.001	0.003	0.001	0.004	0.001	0.003
-2Log likelihood	4999.446		4920.357		4914.923		4909.163		4919.802		4907.182	
N individuals	2283		2283		2283		2283		2283		2283	
N municipalities	233		233		233		233		233		233	

Source: Nivel 2018. Fixed slope, random intercept.
*p<0.05; **p<0.01; ***p<0.001.

***Table 3.5**. Results multilevel analysis of the effect of chronic condition on informal neighborhood participation.*

	Model 7			**Model 8**			**Model 9**		
	B		**S.E.**	**B**		**S.E.**	**B**		**S.E.**
Chronic condition (ref=general population)									
- chronic condition but no impairment	0.034		0.057	0.352		0.272	0.342		0.272
- mild impairment	-0.031		0.062	0.172		0.305	0.180		0.303
- moderate impairment	-0.087		0.056	0.322		0.275	0.299		0.275
- severe impairment	-0.237	**	0.085	-0.313		0.399	-0.290		0.396
Mediators									
Subjective health							-0.001		0.001
Depression							-0.084	**	0.032
Perceived income							-0.003		0.024
Moderators									
Social support policies	0.036		0.042	0.114		0.069	0.114		0.068
Social support policies									
x chronic condition but no impairment				-0.141		0.116	-0.140		0.116
x mild impairment				-0.090		0.127	-0.095		0.126
x moderate impairment				-0.180		0.118	-0.169		0.118
x severe impairment				0.031		0.169	0.025		0.167
Control variables									
Gender (ref=male)	0.156	***	0.041	0.154	***	0.041	0.159	***	0.041
Minority (ref=no)	0.050		0.069	0.051		0.069	0.042		0.069
Household composition (ref=single-person household)	-0,111	*	0.048	-0.111	*	0.048	-0.112	*	0.048
Income (ref=below average)	0.064		0.048	0.070		0.048	0.065		0.051
Age (ref=15-40 years)									
- 40-65 years	0.175	*	0.088	0.176	*	0.088	0.162		0.088
- 65-75 years	0.317	***	0.088	0.314	***	0.088	0.291	**	0.089
- 75 or older	0.302	***	0.091	0.301	**	0.091	0.276	**	0.092
Level of education	0.028		0.029	0.029		0.029	0.029		0.029
Church attendance	0.054	**	0.020	0.051	*	0.020	0.051	*	0.020
Intercept	1.133	***	0.153	0.958	***	0.194	1.188	***	0.248
Variance individual level	0.499		0.020	0.496		0.020	0.493		0.020
Variance municipality level:									
Intercept	.000000b		0.000	0.002		0.004	0.002		0.004
Slope chronic condition:									
- chronic condition but no impairment	.000000b		0.000	.000000b		0.000	.000000b		0.000
- mild impairment	0.004		0.022	0.003		0.022	0.002		0.021
- moderate impairment	.000000b		0.000	.000000b		0.000	.000000b		0.000
- severe impairment	.000000b		0.000	0.003		0.046	.000000b		0.000
-2Log likelihood	2762.699			2759.176			2752.31		
N individuals	1289			1289			1289		
N municipalities	48			48			48		

Source: Nivel 2018. Random slope, random intercept.
*p<0.05; **p<0.01; ***p<0.001.

Model 7 shows the effect of the SSPI on neighborhood participation, which is not significant. Also, none of the interaction effects in model 8 reach significance. We expected that differences between the general population and people who have a chronic condition and/or physical impairment would be smaller in municipalities with a higher SSPI, but this hypothesis (5b) is not confirmed. Although the parameter estimates are in the expected direction, the (interaction) effects of municipality political characteristics on neighborhood participation are not significant.

Finally, we can conclude that the confirmed hypotheses remain accepted when control variables are added to the models, showing that these results are robust.

3.4 Discussion and conclusion

3.4.1 Discussion

The aim of this contribution was to gain insight into the relationship between having a chronic condition or physical impairment and informal social capital and neighborhood participation. In this study, we focused on possible mediating and moderating factors on the individual and municipality level. We used data from two large panel surveys in the Netherlands (the National Panel of people with Chronic condition or Disabilities (NPCD) and the Dutch Health Care Consumer Panel (DHCP)), on which multilevel regression analyses and mediation analyses were conducted to test our hypotheses.

We first expected that people who are more impaired (by a chronic condition) would have less informal social capital and participate less in their neighborhoods than the general population. These expectations were confirmed by our findings for people who are *severely* impaired both with regard to having informal social capital and neighborhood participation. For neighborhood participation, this expectation also holds for people who are *moderately* impaired. We also found that being impaired (by a chronic condition or disability) has a negative relationship with subjective health. In turn subjective health is positively related to social capital, partly explaining the relationship between suffering from a chronic condition or disability and social capital. Furthermore, depression mediates the relationship between chronic condition and/or having an impairment and informal social capital, as well as the relationship between with neighborhood participation. This result confirms existing research that shows that people who suffer from a chronic condition or disability more often experience depression or have a lower subjective health (Pinquart, 2001, Birk et al., 2019), and studies that show that people with depression or a lower subjective health have less social capital (Lin et al., 1999, Portela et al., 2013). In addition to this research we showed that both factors play a role in the negative relationship between having a chronic condition or disability and informal social capital.

Next, we tested if the relationship between having a chronic condition and/or disability and informal social capital and neighborhood participation differed between Dutch municipalities. More specifically, we expected that different political party coalitions in municipalities would be able to help people with a chronic condition to a different extent fostering their informal social capital and neighborhood participation. Based on this idea, we constructed a Social Support Policy Index (SSPI) and expected higher support in municipalities with councilors from local parties, a little less in municipalities with social-democratic councilors, even less in municipalities with corporatist councilors and the least in municipalities with more liberal councilors. However, we found low level 2 variances. Despite this we also found that in municipalities with a higher SSPI-score, differences in informal social capital are smaller for people with a severe impairment. This corresponds to prior research to a limited extent, since it only holds for informal social capital and people with a severe impairment. Still, by studying differential policies of municipalities more specifically, we contributed to existing knowledge on the mechanisms behind the relationship between chronic condition and social capital.

3.4.2 Limitations

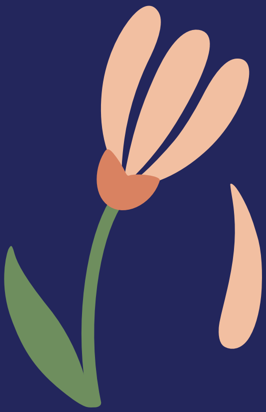
The main limitation of using the DHCP as a sample of the general population is that this data also contains people with a chronic condition or disability. In 2018, almost 60 percent of the Dutch population suffered from a chronic condition. Of this group, approximately half had more than one chronic condition (National Institute for Public Health and Environment, 2018), so it is likely that of the respondents from DHCP a substantial amount also has a chronic condition or disability. This probably caused an underestimation of the relationship between having a chronic condition and social capital. However, it was not possible to distinguish the group with and without a chronic condition or disability in a reliable way. Another limitation of the data is that the NPCD excludes certain groups of people with a chronic condition or disability (namely those who are permanently institutionalized, terminally ill and do not have sufficient knowledge of the Dutch language). This might have resulted in an underestimation of the effects found as well. However, a strength of the data is that people who suffer from a chronic condition from the NPCD are officially diagnosed, which is a more reliable measure than self-reported chronic condition. A third limitation is that the constructed SSPI is a proxy for the actual municipality policies we aimed to include as a relevant context factor in our analyses. First of all, there is no complete data source indicating how Dutch municipalities executed the Social Support Act in 2017. Second, no valid measurement of the policies was available before 2017, on which this research could build. Still, this research does provide knowledge about possible measurements for future research and it underlines the importance of central registration of information on municipal policies for all municipalities in the Netherlands. Another improvement for future research would be to use a larger dataset in order to improve the amount of municipalities that can be included in the analysis.

3.4.3 Conclusions

Given the limitations as beforementioned, our research contributes to the understanding of the relationships between having a chronic condition and/or disability, informal social capital and neighborhood participation. This insight is achieved and based on Dutch data, that are of specific interest in the light of recent policy changes in the Netherlands. This research firstly shows that this approach is relevant, as in the Netherlands differences exist in informal social capital and neighborhood participation between the general population and people who suffer from a chronic condition or disability. We also found that these differences are partly mediated by individual characteristics, specifically depression, while the contextual effect of municipality policies was weak and only of influence for people with a severe impairment. Since self-reliance of people through their social network is an important principle of the Social Support Act, this result emphasizes that policy makers should be aware that psychological health plays a key role in amplifying informal social capital and neighborhood participation.

CHAPTER 4

Social implications of celiac disease or non-celiac gluten sensitivity



A slightly different version of this chapter has been published as:

Vis, E. B. A. & Scheepers, P. L. H. (2017). Social Implications of Celiac Disease or Non-celiac Gluten Sensitivity. *International Journal of Celiac Disease,5(4):* 133-139.doi: 10.12691/ijcd-5-4-3

Vis wrote the manuscript and conducted the analyses. Scheepers substantially contributed to the manuscript. The questionnaire benefitted from feedback of the Dutch Celiac Association.

Abstract

Research has described the perceived social restrictions that people who suffer from celiac disease can experience, but never investigated their actual amount of social contacts. Therefore, we focus on the question whether people who suffer from celiac disease or non-celiac gluten sensitivity have less informal social capital (e.g. contacts with friends and family) than a healthy subpopulation and, if so, which health related factors can explain these differences in social capital. With the aid of the Dutch Celiac Association, we gathered high quality data. Results show that people who are diagnosed with celiac disease or NCGS indeed have less informal social capital than a healthy control group. This can be explained partly by feelings of depression, subjective health and having another chronic condition, but it appears that demographic factors, such as gender, age, having children and marital status, reduce the initial relationship completely. These factors thus play a more important role. Although most of the differences in informal social capital between people who suffer from celiac disease or NCGS and the healthy control group can be explained by demographic characteristics, the findings may help healthcare professionals to interpret social consequences of celiac disease and non-celiac gluten sensitivity in a broader sense.

4.1 Introduction

The impact of celiac disease on people's daily lives (especially health related quality of life) has been investigated regularly. Some research shows that a gluten free diet can significantly improve quality of life after celiac disease diagnosis (Mustalahti yet al., 2002, Nachman et al., 2009). Others showed that celiac disease and a gluten free diet does entail many social restrictions, such as difficulties while eating out or traveling (Lee & Newman, 2003, Rosén et al., 2011, Olsson et al., 2009). Many scholars have stressed the importance of studying the social and psychological impact of suffering from celiac disease (Ciacci et al., 2002, Sverker et al, 2009). Despite the fact that social restrictions that can be present when suffering from celiac disease are described in several studies, it has never been investigated if celiac disease also has a negative impact on the formation of informal social capital, namely contacts with friends, family, neighbors and colleagues.

When it comes to social contacts we explicitly focus on the construct of informal social capital because it has a strong theoretical and methodological base in literature which can be applied well to the subject of this research. Social capital was first conceptualized by Bourdieu (Bourdieu, 1986) and has been complemented by many others. Informal social capital consists of social bonds between individuals (in contrast to informal social capital which consists of civic participation in formal organizations) (Pichler & Wallace, 2007). Many resources that can be invested in social relations, such as economic means (income) or cultural means (knowledge on a variety of subjects, cultural competences related to a certain social status) are important in the attainment of social capital. A lack of these resources could reduce informal social capital (Berkman & Kawachi, 2000, Gesthuizen et al., 2008). It has been argued that good health can also be seen as a resource that fosters social capital because it enables people to participate in social events (Hogan et al., 1993, Haas et al., 2010). Consequently, a lack of health van be a restriction in this resource.

On the basis of this, we argue that having celiac disease can be seen as a lack in resources as well, because of two reasons. First, the gluten free diet can be difficult to follow and can be experienced as restrictive (Hall et al, 2009). A dietary restriction such as a gluten free diet can have a negative impact on the ability to dine out, eat at a friend's place or travel (Lee & Newman, 2003). The restrictions that a gluten free diet imposes on eating outside of the home may impact someone's opportunities to socialize, since social events often involve food. This could reduce the informal social capital of people who suffer from celiac disease or NCGS. Second, celiac disease is a chronic condition. Although complaints should be manageable by following a gluten free diet, some people still experience health complaints (Faulkner-Hogg et al., 1999, Wahab et al, 2002) which can impose restrictions on people's daily lives, including opportunities to gain and maintain informal social capital by participating in social events.

Different studies have shown that people with celiac disease are more vulnerable to other health related issues such as depression (Smith & Gerdes, 2012), a variety of physical symptoms (Faulkner-Hogg et al., 1999), a lower subjective health (Hallert et al., 1998, Lohiniemi et al, 1998) or other chronic conditions (Green & Jones, 2010). These factors can induce (extra) difficulties in investing in and maintaining social relations and may have a negative effect on group participation (Haas et al., 2010, Lin et al., 1999, Pollack & von dem Knesebeck, 2004, Da Silva et al., 2007, Charmaz, 1983, Fougeyrollas, 2000). We will take these individual health related characteristics into account as possible explanations for differences in social capital between people who suffer from celiac disease and the healthy control group. Since there appear to be more reasons than celiac disease to adopt a gluten free diet, mainly NCGS, we will take this group into account as well, in contrast to prior research.

Consequently, we address the following research questions:

(1a) *To what extent do people who suffer from celiac disease or NCGS differ from the general population in terms of social capital?* and

(1b) *If there are differences, to what extent can they be explained by individual (health related) characteristics?*

4.2 Data and methods

4.2.1 Data description

For this research we made use of non random convenience sampling utilizing the membership file of the Dutch Celiac Association. We sent an e-mail with a questionnaire to all members who stated they would be willing to participate in any scientific research with their registration as a member. Thereafter, we asked all respondents to send a questionnaire to one friend or acquaintance. With this approach, our goal was to find a healthy control group, which resembled the people who suffer from celiac disease or NCGS on some important characteristics such as gender and age, but were not so close to the respondent that a bias would occur considering social capital. The questionnaire for friends or acquaintances was similar to the questionnaire received by people with celiac disease or NCGS, except for the fact that we asked an extra question about the relationship with the person who sent the respondent the second questionnaire and we left out specific questions about celiac disease or NCGS and the gluten free diet.

The Dutch Celiac Association had approximately 17.000 members at the time of the data collection. Of these members 4.673 stated they were willing to take part in scientific research and were sent the questionnaire and letter. In total, 1.167 members filled in the questionnaire. Consequently, the response rate is 25 percent[1]. It was not possible to determine how many people sent the questionnaire to a friend or acquaintance, so the response rate of this questionnaire cannot be estimated. This questionnaire was filled in by 163 people.

It was not possible to test for representativity extensively, because we only know something about the prevalence of celiac disease regarding gender. Celiac disease is two to three times more common in women than in men (Dutch Celiac Association, 2008). The people who filled in the first questionnaire through the Dutch Celiac Association seem to match these criteria: 73.9 percent is female and 26.1 male, which resembles the gender specific prevalence of celiac disease in the total population.

After exclusion of all cases with missing values (except for income), the dataset consisted of 1256 people, of which 1097 filled in the first questionnaire and 159 filled in the second questionnaire.

4.2.2 Operationalization

We measured informal social capital with the following questions: How often do you have personal contact with the following people: (1) family, (2) friends, (3) colleagues/classmates and (4) neighbours. We explicitly stated that this question only covered offline, face to face contact. A factor analysis and reliability check showed that creating a scale measuring contact with family, friends and colleagues/classmates led to the highest reliability (α=0.49). Although a Cronbach's alpha with a minimum value of 0.60 is desirable (De Heus et al., 1995), we decided to construct a scale with three

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[1] ((1.167/4.673)*100)

variables (leaving the item about neighbours out) to take into account theoretical as well as methodological considerations. On this scale a higher score means a higher level of informal social capital.

We asked respondents if they had celiac disease, NCGS or none of these diagnoses. Furthermore, we asked about how their diagnosis was given. We based these questions on the current guidelines for the diagnosis of celiac disease (Fasano & Catassi, 2015, Dutch Association of Gastroenterologists, 2008) and on the Salerno criteria (Catassi et al., 2015) when it comes to NCGS. To determine which people did not suffer from celiac disease or NCGS, we included the respondents of the second questionnaire, who indicated not to follow a gluten free diet. Consequently, we distinguished four groups: (1) people who suffer from celiac disease (official diagnoses) who eat gluten free, (2) people with an unofficial celiac disease diagnosis who follow a gluten free diet, (3) people who suffer from NCGS (official and non official diagnoses) who eat gluten free and (4) people without celiac disease or NCGS who do not follow a gluten free diet.

Depression was measured by the CES-D scale (Center of Epidemiological Studies Depression Scale). We found these questions to form a reliable scale (α=0.81) on which a higher score means a higher amount of depressive symptoms, including for example: feelings of sadness, loneliness or depression, problems with sleeping and troubles to ‘get going’.

To measure physical health we asked people how often in the past four weeks (on a four point scale from almost never to almost always) they experienced certain physical symptoms that are related to celiac disease, namely: pain in general, abdominal complaints (Faulkner-Hogg et al., 1999), fatigue (Dewar et al., 2012) and problems with concentrating (Green & Jones, 2010). A reliable scale was made with a Cronbach’s alpha of 0.75 which indicates the amount of physical problems people experience. A higher score means that someone experiences more symptoms.

We measured subjective health with the question ‘How is your health in general?’ (Huijts, 2011). Respondents could answer on a five point scale ranging from very bad to very good. Furthermore, we asked all respondents whether they had a chronic condition or other food-intolerance/allergy. Answer categories were no or yes, namely: diabetes, thyroid disease, Dermatits Herpetiformis, rheumatic disease, lactose intolerance or other, namely. For the analyses, we divided people into two categories: those who did have another chronic condition and those who only had celiac disease or

NCGS, or did not have a disease at all (in case they belonged to the healthy control group).

As control variables, we included several resources known to influence informal social capital. We took into account education, measured with the ISCED-scale (UNSECO, 2015) later composed into three dummy categories ((1) primary and lower secondary education, (2) upper and post secondary education, (3) tertiary education, first and second stage) on the basis of linearity checks. Income was classified as below average (up to 2100 euros a month) and above average (more than 2100 euros). Extra categories were created for people who did not know or did not want to indicate their income. When it comes to marital status, we distinguished people who are single, with a partner but not married or cohabiting, married or cohabiting, divorced, and widowed. Furthermore, we made a distinction between people who have no children, children who live at home or children who do not live at home. Also, we asked respondents about how often they attend religious services: (almost) never, a few times a year, around once a month or around once a week. At last, we included gender (1=female) and age (18 to 93).

Descriptive statistics of all variables can be found in Table 4.1 and 4.2.

Table 4.1. *Descriptive statistics of continuous variables.*

	Min.	**Max.**	**Mean**	**S.D.**
Informal social capital	0	6	3.17	1.05
Depression	0	2.75	0.75	0.48
Physical symptoms	0	3	0.88	0.64
Subjective health	0	4	2.66	0.74
Church attendance	0	3	0.67	1.07
Age	18	93	53.92	16.44

N=1256

4.3 Results

For our analyses we used lineair regression analysis, performed in IBM SPSS Statistics 21.

4.3.1 Celiac disease/NCGS and informal social capital

First we tested the bivariate relationship between suffering from celiac disease or NCGS and informal social capital in Model 1 of Table 4.3. This shows that people who suffer from celiac disease (officially diagnosed) have less informal social capital than the healthy control group (b=-.302). People with an unofficial celiac disease diagnosis and NCGS have less informal social capital as well (b=-.299 and b=-.341).

***Table 4.2**. Descriptive statistics of categorical variables.*

	N	% cat. 1
Celiac disease/NCGS		
• No CD/NCGS	159	12.7
• Official celiac disease diagnosis	920	73.2
• Unofficial celiac disease diagnosis	79	6.3
• NCGS	98	7.8
Income		
• Below average	341	27.1
• Above average	724	57.6
• Don’t know	43	3.4
• Don’t want to tell	148	11.8
Level of education		
• Primary and lower secondary	228	18.2
• Upper and post secondary	395	31.4
• Tertiary	633	50.4
Having a (chronic) condition		
• No	661	52.6
• Yes	595	47.4
Gender		
• Male	328	26.1
• Female	928	73.9
Marital status		
• Married or cohabiting	866	76.1
• Together not married/cohabiting	88	7.0
• Divorced	36	2.9
• Widow	45	3.6
• Single	143	11.4
Having children		
• No children	388	30.9
• Children at home	327	26.0
• Children not at home	541	43.1

N=1256

4.3.2 Mediating factors: depression, physical symptoms, subjective health and other chronic conditions

Model 2 to 5 show the effects of depression, physical symptoms, subjective health and having (another) chronic condition. In Model 2 it can be seen that people who experience depression have less informal social capital (b=-.302). Depression reduces the initial relationship between suffering from celiac disease or NCGS and informal social capital with 13.6[2] (for people with an official celiac disease diagnosis), 15.7[3] percent (for people with an unofficial celiac disease diagnosis) and 27.0[4] (for people with NCGS) percent. It appears that physical symptoms do not influence the amount of informal social capital (Model 3) and that people who report to have a better subjective health have more contacts with friends, family and colleagues/classmates (b=.164) (Model 4). Also, subjective health explains 17.8[5] (official celiac disease diagnosis), 14.7[6] (unofficial celiac disease diagnosis) and 31.1[7] (NCGS) percent of the initial relationship between suffering from celiac disease or NCGS and informal social capital. Model 5 shows the effect of having another chronic condition. It appears that people who have a chronic condition (next to celiac disease or NCGS) have less social capital (b=-.231). Having another chronic condition reduces the initial relationship with 20.8[8] (official celiac disease diagnosis), 27.1[9] (unofficial celiac disease diagnosis) and 36.4[10] (NCGS) percent.

To investigate the effects of depression, physical symptoms, subjective health and (other, chronic) conditions more in depth we use a method described by Preacher and Hayes (2008) which not only checks the significance of these factors on informal social capital, but also the effect of having celiac disease or NCGS on these mediating factors (Figure 4.1).

For depression, subjective health and having another chronic condition a completely significant mediation effect was found. This means that these factors significantly influence informal social capital, but also are influenced by suffering from celiac disease or NCGS. The effect of physical symptoms on informal social capital appeared to be insignificant. However, the extra analysis as showed in Figure 4.1 shows that people who suffer from celiac disease or NCGS do tend to experience more physical symptoms.

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[2] (-.302)-(-.261)/-.302*100=13.6%

[3] (-.299)-(-.252)/-.299*100=15.7%

[4] (-.341)-(-.267)/-.341*100=21.7%

[5] (-.302)-(-.248)/-.302*100=17.8%

[6] (-.299)-(-.255)/-.299*100=14.7%

[7] (-.341)-(-.235)/-.341*100=36.3%

[8] (-.302)-(-.239)/-.341*100=20.8%

[9] (-.299)-(-.218)/-.299*100=27.1%

[10] (-.341)-(-.217)/-.341*100=36.4

Table 4.3. *Results linear regression analysis of the effect of suffering from celiac disease/NCGS on informal social capital.*

	Model 1		**Model 2**		**Model 3**		**Model 4**		**Model 5**		**Model 6**		**Model 7**	
	B	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**
Intercept	3.438***	.083	3.590***	.091	3.452***	.088	3.022***	.153	3.486***	.084	4.893***	.180	4.856***	.240
CD/NCGS (ref = healthy control group)														
Official CD diagnosis	-.302***	.090	-.261***	.090	-.297***	.091	-.248***	.091	-.239***	.091	-.091	.083	-.014	.083
CD unofficial diagnosis	-.299**	.145	-.252*	.144	-.293**	.145	-.255*	.144	-.218	.146	-.189	.131	-.108	.130
NCGS	-.341**	.135	-.267**	.135	-.327**	.139	-.235*	.137	-.217	.138	-.216*	.122	-.085	.125
Mediators														
Depression			-.302***	.061									-.345***	.068
Physical symptoms					-.022	.047							.061	.057
Subjective health							.164***	.041					.075	.046
Having a (chronic) condition (1=yes)									-.231***	.061			-.100*	.058
Control variables														
Level of education (ref = primary/lower secondary)														
Upper/post secondary											.064	.083	.053	.082
Tertiary											-.016	.082	-.029	.080
Income (ref = below average)														
Above average											.068	.073	.018	.073
Don’t know											-.014	.154	-.020	.152
Don’t want to say											.121	.098	.076	.097
Marital status (ref = single)														
Married or cohabiting											-.312***	.103	-.365***	.102
Together with partner (not married/cohabiting)											-.131	.130	-.195	.128
Divorced											-.430**	.183	-.386**	.181
Widowed											-.188	.173	-.238	.170

Table 4.3. *(continued)*

	Model 1		**Model 2**		**Model 3**		**Model 4**		**Model 5**		**Model 6**		**Model 7**	
	B	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**	**B**	**S.E.**
Having Children (ref=no children)														
Children living at home											.070	.079	.063	.077
Children not at home											.216**	.087	.177**	.086
Gender (1=female)											.106*	.064	.160**	.065
Age											-.030***	.002	-.029***	.002
Church attendance											.028	.025	.023	.025
R^2	.009		.029		.010		.022		.021		.218		.249	
Adjusted R^2	.007		.025		.006		.019		.017		.207		.236	

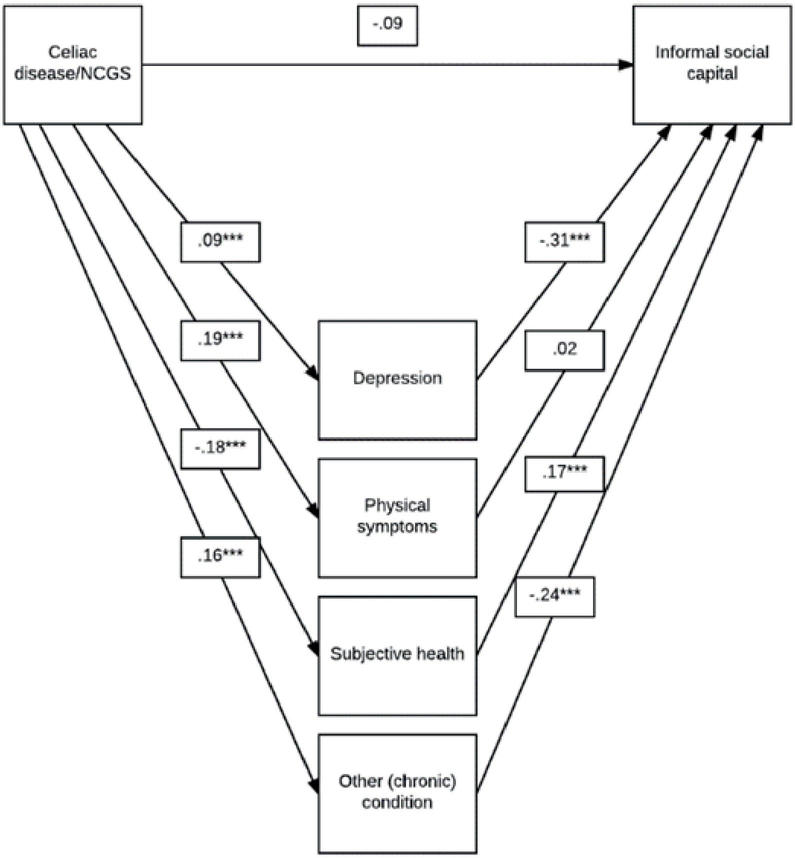

Figure 4.1. *Preacher and Hayes analysis on the mediating factors of the relationships between celiac disease or NCGS and informal social capital.*

4.3.3 Demographic characteristics

The influence of relevant demographic characteristics is shown in Model 6. Including these characteristics reduces differences between suffering from celiac disease or NCGS and informal social capital to non-significance, implying that the initial differences are due to these factors.

It appears that people who are married or cohabiting and people who are divorced see their friends, family and colleagues/classmates less often than singles (b=-.312 and b=-.430). Having children who do not live at home has a positive effect on informal social capital (b=.216). Lastly, women and younger people have more frequent contact with friends, family and colleagues/classmates. (b=.106 and b=-.030).

In Model 11, all mediators and control variables are shown. The majority of the effects of the mediating and control variables do not differ from the other models, which implies that the findings are robust. Only the mediating effect of subjective health changes from positive and significant to a slightly positive and non-significant effect.

4.4 Discussion and conclusion

With this contribution we aimed to gain insight in the relationship between suffering from celiac disease or NCGS and informal social capital. We enriched previous literature in several ways. First, previous studies took into account perceived social restrictions considering celiac disease and the gluten free diet, while in this research, we looked at the actual amount of social contacts. Second, we compared celiac disease or NCGS patients with a healthy control group and made an explicit distinction between having celiac disease or NCGS, which has not been done before.

By making use of the membership file of the Dutch Celiac Association to send out a questionnaire, we gathered high quality data to answer our research questions.

Certain resources (for example income or education) can positively influence social capital (Berkman & Kawachi, 2000, Gesthuizen et al., 2008). In this research, we argued that suffering from celiac disease or NCGS can be seen as a lack of resources and thus a constraint in the formation and maintenance of social capital. Furthermore, we investigated whether differences in informal social capital between the healthy subpopulation and people who suffer from celiac disease or NCGS could be explained by several factors related to health, namely feelings of depression, physical symptoms, subjective health and having another chronic condition.

It appears that people who suffer from celiac disease or NCGS indeed have less informal social capital than a healthy subpopulation. The fact that celiac disease and NCGS patients have less social contacts can be explained by several characteristics, namely the factors depression, subjective health and having another chronic condition. However, these factors do not explain the initial relationship between suffering from celiac disease or NCGS and informal social capital completely. It appears that several demographic variables play a more important role, since these factors do reduce the effects of having celiac disease or NCGS to non-significance.

On the basis of the outcomes, we argue that celiac disease or NCGS can indeed be seen as a constraint in the formation of informal social capital. The described expected relationships of celiac disease or NCGS on the formation of informal social capital and the effects of depression, subjective health and other chronic illnesses seem to hold and should be taken into account as risk factors for social isolation in clinical practice. However, the fact that differences in social capital are reduced completely by demographic variables is very important and shows that gender, age and household characteristics (marital status and having children) play a large role as well.

Our comparison with a healthy control group proved to be fruitful, but as a result the methodological and analytical strategy was more challenging. A sample of healthy people which is not, or less, dependent on the group of people who suffer from celiac disease or NCGS is something to consider in future research.

To conclude, we showed that not only perceived social restrictions are important to take into account (as previous research demonstrated), but that the actual amount of social contacts of people who suffer from celiac disease or NCGS can be deprived as well. Although most of the differences in informal social capital between people who suffer from celiac disease or NCGS and the healthy control group can be explained by demographic characteristics, professionals and future research should take into account that celiac disease or NCGS patients who suffer from depression, a lower subjective health or several chronic conditions can be at risk for having a smaller amount of social capital.

CHAPTER 5

Healthcare utilization and informal social capital of people who have a chronic condition in the Netherlands

A slightly different version of this paper has been submitted to an international peer-reviewed journal.

Juliane Menting, Peer Scheepers and Ronald Batenburg are co-authors of this paper. Vis conducted the analyses and wrote the manuscript. Scheepers, Batenburg and Menting substantially contributed to the manuscript.

Abstract

This research investigates the relationship between the level of physical impairments (of people with a chronic condition) and healthcare utilization. Furthermore, we investigate the role of informal social capital in this relationship which is especially relevant in light of the Social Support Act. This Act determines that municipalities are responsible for parts of the care of people with a chronic condition and in which a key principle is that people rely on their own network before receiving care of municipalities. Based on the Behavioral Model of Healthcare Utilization and prior research, we hypothesize the level of impairment to be an important determinant of healthcare utilization, and that informal social capital either promotes or reduces the likelihood of using different types of care. We also investigate whether the effect of informal social capital differs for people with different levels of impairment (moderation effects). We distinguish two types of healthcare utilization, based on two policy laws in the Netherlands: 'SSA care' that is regulated by the Social Support Act (SSA), and 'HIA care' that is governed by the Health Insurance Act (HIA). Within HIA care we compare five different types of care. We use data from the Dutch National Panel of people with Chronic illness or Disabilities and logistic regression analyses. We find that for both SSA and HIA care, people with a physical impairment are more likely to use these types of care, compared to people with a chronic condition but no physical impairment. Informal social capital reduces the likelihood to use SSA care and psychological (HIA) care. We did not find any moderating effects however, showing that the relationship between the level of physical impairment and the use of both SSA and HIA care is not different for people with less or more informal social capital.

5.1 Introduction

In 2018, almost 60 percent of the Dutch population had one or more chronic conditions and approximately one in eight people experienced physical limitations regarding movement, seeing or hearing (National Institute for Public Health and Environment, 2020). This causes challenges for the Dutch healthcare system, which was reformed around 2006 and 2015 (Kroneman et al., 2016; Ministry of Health, Welfare and Sport, 2001). In 2006, the Dutch Health Insurance Act (HIA) was introduced (in Dutch: *Zorgverzekeringswet*, ZVW), in which a basic health insurance is mandatory for all citizens and can be expanded with supplementary health insurance that, for example, cover more health services such as physiotherapy costs or dental care for adults. Several health insurers are expected to compete for customers, and at the same time need to ensure that health providers compete for contracts on price and quality. In addition, the governance of long-term care (for example support with daily tasks, mobility aids, taxi services, adult day care services or sheltered housing) was transferred to municipalities by the Social Support Act in 2007 and 2015 (SSA, in Dutch: *Wet Maatschappelijke Ondersteuning*, WMO) (Jeurissen and Maarse, 2021). Since then, municipalities receive state subsidies to define their own policies for providing long-term care to their citizens. The idea behind this transformation is that municipalities are better able to offer high quality and efficient care suited to the needs of their inhabitants (Kroneman et al., 2016). Also, one of the starting points of the SSA is to promote self-reliance and to include social networks to provide informal care and support when possible.

In this context, the question arises what factors determine healthcare utilization of people with a chronic condition and/or disability. Since the SSA is specifically designed to support the usage of one’s social network, this factor is especially relevant. To investigate this, we will build upon the Behavioral Model of Health Services Use and literature on informal social capital.

In the Behavioral Model of Health Services Use, originating from the 1960s and later revisited by many (for example Andersen, 1995), it is theorized that not only demographic characteristics and the actual need for healthcare explain healthcare utilization, it is also argued that there are “enabling factors” that play a role (Andersen, 1995). These enabling factors can be the availability of healthcare personnel, access to health insurance, knowledge about the availability of healthcare or income. Another factor that can play a role according to this model are social interactions. We argue that informal social capital is one of those social determinants. The definition of informal social capital was coined by Bourdieu (1986) and is complemented by many others. Informal social capital mainly consists of informal bonds between people (Pichler and Wallace, 2007), in which one needs to invest and in turn resources are available through these bonds. Based on the Behavioral Model of Health Services Use we expect that the actual need for healthcare, for example because someone has a chronic condition and/or a physical impairment, is an important determinant for healthcare utilization. Several studies have been carried out investigating the relationship between health and healthcare utilization. It has been shown that self-rated health and multimorbidity are associated with the utilization of primary care including general practitioner (GP) visits, or hospitalization (Broemeling et al., 2008; Hopman et al., 2016; Loef et al., 2021).

Next to this, informal social capital can influence healthcare utilization in different ways. First, informal social capital can improve knowledge about health, healthcare services or healthcare providers (Andersen, 1995; Deri, 2005), or can offer practical support to visit healthcare providers. This argument is supported by Fjaer et al., (2017) who found that in several European countries people with more social capital were more likely to consult a medical specialist. Second, informal social capital may influence healthcare utilization in another way as well: social capital can offer practical support by providing informal care or help with daily tasks. This is supported by Bolin et al. (2008) who found that informal care, mostly offered by informal social capital, can substitute formal home care for the elderly. They also found however, that informal care can be an addition to care provided by medical specialists during hospital visits. In addition, Berker et al. (2021) found that contact with neighbors can decrease the likelihood of using SSA-care.

Based on the above, we hypothesize that (1) the level of physical impairment of people with chronic conditions is an important determinant of different types of healthcare utilization, and (2) that informal social capital will moderate this relationship in the following manner:

- For care that is regulated by the Social Support Act ('SSA-care'), we hypothesize that informal social capital can compensate the utilization of this type of care. SSA-care mainly consist of practical support with daily activities, for example personal hygiene, cleaning and cooking. One of the starting points of the Social Support Act is that people should rely on their own network as much as possible, before receiving support from the municipality. Hence, we expect that the relationship between level of physical impairment and use of SSA-care will be weaker for people with more informal social capital.

- For care that is governed by the Health Insurance Act ('HIA-care'), we hypothesize that informal social capital can offer possibilities for practical support to find and enable visits to professional services (for example transportation from and to a hospital, access to health services), HIA-care is mainly carried out by certified professionals (medical specialists, GPs) and financed by national health insurance budgets. Hence, we expect that the relationship between level of physical impairment and use of HIA-care will be stronger for people with more informal social capital.

By testing these hypotheses, we add to existing research. To the best of our knowledge, no research has been carried out in the Netherlands that analyzes the utilization of *different* types of healthcare services, in relation to the informal social capital of people with chronic conditions, and linking this with social policy contexts. This paper is structured by answering the following two research questions:

(1) *To what extent do people with chronic conditions vary in their healthcare utilization, depending on the type of health service provision and their level of physical impairment?*
(2) *And if there are differences, to what extent does informal social capital moderate the relationships between level of chronic conditions on the one hand, and utilization of the different types of healthcare services on the other?*

5.2 Data and methods

5.2.1 Data

Our analyses are based on data collected by the National Panel of people with Chronic illness or Disabilities (NPCD) in 2018. The NPCD is a representative and nation-wide panel in the Netherlands governed by the Netherlands Institute of Health Services Research (Nivel). The panel consists of people of 15 years or older, who live independently and have a medically diagnosed illness and/or a physical disability. Members of the panel are recruited via general practitioners and population screenings by Statistics Netherlands. The aim of the panel is designed to monitor the consequences of living with a chronic condition or a disability. Panel members receive questionnaires twice a year (Menting et al., 2019). The response rate for the 2018 data used in this research was 75% (Menting et al., 2019).

Protection of the data is registered with the Dutch Data Protection Authority (NPCD: 1283171). Data are processed anonymously and handled in accordance with the privacy protection guidelines of the Dutch Data Protection Authority (in Dutch: *Algemene Verordening Gegevensbescherming*, AVG). According to Dutch legislation, obtaining informed consent or approval by a medical ethics committee is not mandatory for carrying out research in this panel, but privacy regulations do apply.

For the present study, we included people with at least one chronic condition. After listwise exclusion of respondents with missing values on the variables included in analyses we included 903 respondents in the analyses.

5.2.2 Measurement of the different types of healthcare utilization

The use of Social Support Act (SSA) care was measured using the survey question: "Have you had professional help with domestic chores through the Social Support Act in 2017? If yes, how much? Examples are: help with cooking, grocery shopping, laundry, cleaning etc.". Next to this, the usage of Dutch Health Insurance Act (HIA) care was measured by asking panel participants whether they had had contact with different healthcare professionals in the last 12 months, namely: the GP (excluding GP care in evenings/nights and weekends, but including contact with practice nurses), medical specialists, paramedical professionals[1] and psychologists/ psychiatrists or a mental health institution.

Of the respondents, 27 people (1.6%) did not answer the question regarding SSA-care. For HIA-care (psychological care, care by a GP, medical specialist or paramedical specialist), respectively 72 (4.3%), 30 (1.8%), 36 (2.1%) and 64 (3.8%) respondents did not answer the question.

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[1] Including: physiotherapist, dietician, podiatrist, remedial/cesar/mensendieck therapists, occupational therapist, speech therapist, orthoptist, dental hygienist.

5.2.3 Measurement of the level of physical impairment

Participants in the NPCD are included if they are officially diagnosed by a GP with a chronic condition. The measurement of their physical impairment is based on 27 items, i.e. activities that people can do with or without difficulty.[2] This (self-reporting) method is validated and frequently used to determine the level of physical impairment (de Klerk et al., 2006). People without a chronic condition were not included in the analysis (N=7; 0.6%). Also for 497 people it was unknown whether they had a chronic condition (497; 29.6%). For our analyses, we distinguished four groups of physical impairment: (1) chronic condition but no physical impairment, (2) chronic condition and a mild physical impairment, (3) chronic condition and a moderate physical impairment, (4) chronic condition and a severe physical impairment. For 73 people (4.4%) the level of physical impairment could not be determined.

5.2.4 Measurement of informal social capital

Informal social capital was measured combining the questions “How often do you socially meet with (1) (grand)children, (2) relatives, (3) friends, (4) neighbors?”. Answering categories were: at least once a week, twice a month, once a month, less than once a month, (almost) never and not applicable. People who did not have (grand)children, relatives, friends or neighbors and thus stated the item was not applicable were categorized into the category (almost) never. Cronbach’s alpha value over the four items was 0.5. Deleting one or more items from the scale did not improve its reliability. While according to de Heus et al. (1995) a Cronbach’s alpha of at least 0.60 is considered eligible, we chose to continue our analysis with this scale for two reasons. First, we aim to build upon prior research has used the same scale (e.g. Savelkoul et al., 2011). And second, the scale fits our research questions best by taking into account the social network as a whole. In total 77 people could not be included in the scale (4.6%).

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[2] Standing 10 minutes, sitting 10 minutes, 30 minutes standing/sitting, getting up or sitting down, getting in and out of bed, getting dressed/putting on shoes, climbing the stairs, entering or leaving a house, getting around out of the house, washing hands and face, washing my whole body, using the toilet, walk for 10 minutes without a break, daily groceries, preparing a hot meal, change bedding, doing laundry, using kitchen stairs, light domestic chores (dusting, doing the dishes), heavy domestic chores (mopping, cleaning windows), small repairs around the house (answering categories: *I can do this without problems, I can do this with effort, I cannot do this)* problems with eyesight, problems hearing (answering categories: *good/moderate/bad*).

5.2.5 Measurement of the control variables

We included five control variables in our analyses that have been found in earlier research as relevant for health care utilization. We controlled for church attendance (Benjamins and Brown, 2004; Benjamins, 2006), age (Newall et al., 2014), income (Fjaer et al., 2017), level of education (Newall et al., 2014; Fjaer et al., 2017), sex (Bertakis et al., 2000; Ladwig et al., 2000; Pinhashov et al., 2010) and household composition (Henning-Smith, 2016). Church attendance was measured by the question “How often do you attend a religious meeting?” (At least once a week, at least once a month, less than once a month, (almost) never). This variable was coded so that a higher score means a higher church attendance. 91 respondents (5.4%) did not answer this question. Age ranged from 16 to 98 years old. Income was measured by the question “Can you indicate your household’s income after taxes in 2017 (so last year)?” The categories were divided in above or below average (€2,100) corresponding as much as possible with calculations of the Netherlands Bureau for Economic Policy Analysis (CPB, 2016). In total, of 128 respondents (7.6%) income was not known. Level of education was categorized into three groups: low (primary vocational education), medium (applied university) and high (university) educational level. Of 55 people, their level of education was unknown (3.3%). Furthermore we controlled for gender (1=female) and household composition (1=multi-person household). Household composition could not be determined for 24 people (1.4%). We also controlled for the distance to the nearest hospital, general practice and level of urbanization (very strong to very little). These were retrieved from Statistics Netherlands and matched with the living location data of respondents. Table 5.1 shows the descriptive statistics of all variables included in the analyses.

5.2.6 Strategies for analysis

To test our hypotheses we used logistic regression models. For each of the five types of care use as the dependent variables (use of SSA-care, and the four types of HIA-care (psychological care, GP care, paramedical care and care of a medical specialist)) we used similar models. For each dependent variable we first tested, in Model 1, the direct relationship between the level of impairment and healthcare utilization. The second model takes all control variables into account, to analyze whether this relationship is spurious. Models 1 and 2 address our first research question.

***Table 5.1**. Descriptive statistics.*

	N	% in category 1	Min	Max	Mean	S.D.
Continuous variables						
Informal social capital	903		1	5	3.5	0.9
Age	903		17	98	67.4	12.0
N km to hospital	903		1.2	28.4	5.1	4.3
N km to GP	903		0.5	2.5	1.0	0.3
Categorical variables						
SSA-care						
• No	811	89.8				
• Yes	92	10.2				
Psychological care						
• No	822	91.0				
• Yes	81	9.0				
GP						
• No	70	7.8				
• Yes	833	92.3				
Medical specialist						
• No	194	21.5				
• Yes	709	78.5				
Paramedical care						
• No	290	32.1				
• Yes	613	67.8				
Chronic condition						
• No impairment	261	28.9				
• Mild impairment	241	26.7				
• Moderate impairment	301	33.3				
• Severe impairment	100	11.1				
Church attendance						
• (almost) never	718	79.5				
• Less than once a month	43	4.8				
• At least once a month	46	5.1				
• At least once a week	96	10.6				
Education						
• Low	239	26.5				
• Middle	417	46.2				
• High	247	27.4				
Gender						
• Male	404	44.7				
• Female	499	55.3				
Income						
• Below average	391	43.3				
• Above average	512	56.7				
Household composition						
• One person	246	27.2				
• More than one person	657	72.8				
Degree of urbanization						
• Very strong	124	13.7				
• Strong	316	35.0				
• Moderate	162	17.9				
• Little	237	26.3				
• Very little	64	7.1				

To answer our second research question, the relationship between level of physical impairment and healthcare usage is further analyzed by including informal social capital of the respondents with a chronic condition as a moderator in Models 3-4. We first included informal social capital into the models to test its *direct* effect on healthcare utilization. Thereafter, we included the *interaction terms* between informal social capital and physical impairment level, to test the moderating effect of informal social capital. All analyses were conducted with Stata 15.0 (StataCorp., 2017).

5.3. Results

5.3.1 Effects of level of physical impairment on healthcare utilization

We hypothesized that the higher the level of impairment of people with a chronic condition, the more likely they are to use the different types of care.

For *SSA-care*, this relationship is confirmed for respondents with a moderate or severe physical impairment (table 5.2, model 1 and 2). People with a chronic condition who have a mild physical impairment also have a higher chance of using this type of care than people with a chronic condition but no physical impairment, but this effect does not reach significance.

For *HIA-care*, results vary between the specific types of care. For psychological care, the expected relationship only holds for the groups with a mild or moderate physical impairment (table 5.3, model 1 and 2). For care by a medical specialist and paramedical care the relationship is fully confirmed: the higher the level of physical impairment, the more likely it is that people with a chronic condition use this type of care (table 5.5 and 5.6, model 1 and 2). GP care is more likely to be used by the groups with a mild, moderate or severe physical impairment, but the pattern is not linear (table 5.4, model 1 and 2).

5.3.2 Control variables

For SSA-care, table 5.2 (model 2) shows that age increases the likelihood to use this type of care, while a higher income and living in a multi-person household decreases the chance of using SSA-care.

Table 5.2. *Results effect of chronic illness on SSA-care.*

	Model 1				**Model 2**				**Model 3**				**Model 4**			
	OR	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**	
Chronic illness (ref=chronic illness but no impairment)																
- slight impairment	6,638	7,195	0,793	55,545	4,486	4,948	0,516	38,969	4,218	4,659	0,484	36,757	2,881	9,873	0,003	2380,361
- moderate impairment	49,328***	50,029	6,758	360,077	31,763**	32,840	4,186	240,990	28,888**	29,894	3,801	219,561	13,177	40,980	0,030	5848,053
- severe impairment	152,698***	156,227	20,557	1134,238	116,194***	122,141	14,805	911,908	95,457***	100,561	12,108	752,532	101,044	316,480	0,218	46832,770
Moderators/mediators																
Social capital									0,678 **	0,100	0,508	0,904	0,601	0,529	0,107	3,375
x slight impairment													1,122	1,111	0,161	7,807
x moderate impairment													1,268	1,141	0,217	7,396
x severe impairment													0,977	0,886	0,165	5,783
Control variables																
Gender (ref=male)					1,806	0,548	0,996	3,275	2,041*	0,639	1,105	3,771	2,040*	0,641	1,102	3,778
Age					1,030*	0,013	1,005	1,057	1,032*	0,013	1,007	1,059	1,032*	0,013	1,007	1,059
Income (ref=below average)					0,137***	0,057	0,060	0,311	0,143***	0,060	0,062	0,327	0,143***	0,061	0,062	0,330
Education (ref=high)																
- middle					0,873	0,368	0,382	1,994	0,917	0,391	0,398	2,113	0,910	0,389	0,394	2,103
-low					1,175	0,526	0,488	2,827	1,351	0,616	0,552	3,303	1,352	0,619	0,552	3,315
Household composition (ref=single-person household)					0,261***	0,080	0,143	0,477	0,279***	0,087	0,151	0,514	0,276***	0,086	0,150	0,510
Church attendance (ref=never)																
- less than once a month					2,450	1,604	0,679	8,841	2,447	1,620	0,669	8,955	2,555	1,707	0,689	9,467
- once a month or more					0,799	0,627	0,172	3,720	0,723	0,570	0,154	3,387	0,769	0,603	0,165	3,580
- once a week or more					1,129	0,514	0,463	2,755	1,247	0,572	0,507	3,066	1,252	0,573	0,511	3,068
Urbanization																
- Little					4,241	4,838	0,453	39,666	4,082	4,585	0,452	36,899	3,895	4,372	0,431	35,155
- Moderate					7,451	8,491	0,798	69,540	7,805	8,751	0,867	70,266	7,504	8,399	0,837	67,295
- Strong					3,898	4,396	0,427	35,550	3,611	4,010	0,410	31,830	3,398	3,773	0,386	29,947
- Very strong					7,126	8,099	0,768	66,113	6,393	7,157	0,713	57,350	6,258	6,992	0,700	55,908
Intercept	0,004***				0,000***				0,002***				0,002			
Log likelihood	-232,616				-171,553				-167,980				-167,606			

Source: Nivel 2018. *p<0.05; **p<0.01; ***p<0.001

For the four types of HIA-care, we see that older people are less likely to use psychological care (table 5.3, model 2). Age, living in a household with more people and visiting a church once a week or more increases the chance of visiting a GP (table 5.4, model 2). Women and people who have an above average income are more likely to use paramedical care. A lower level of education decreases the likelihood to use paramedical care (table 5.5, model 2). None of the control variables have a significant effect on use of care by medical specialists (table 5.6, model 2).

5.3.3 Moderating effects of informal social capital

With regard to our second research question we see mixed results. Informal social capital has a negative effect on use of SSA-care (table 5.2, model 3). No significant moderating effects were found however, as the interaction terms of level of impairment with informal social capital in model 4 are not significant.

For most types of HIA-care, there are positive but non-significant effects of informal social capital on healthcare utilization. An exception is the use of psychological care. For this type of HIA-care, informal social capital has a significant negative effect (table 5.3, model 3) – indicating that people with higher levels of informal social capital have a lower chance of using psychological care. However, no significant moderator effects were found for this type of care, and the same holds for the usage of the other types of HIA-care.

5.3.4 Summary of the results

Table 5.7 summarizes the results of this study. For research question one, we expected that the higher the level of impairment, the higher the need for healthcare services and the chance to use those healthcare services. This expectation is confirmed for paramedical care and care by medical specialists. For the other types of care, we see that people who have an impairment do have a higher likelihood to use the healthcare services but the patterns are not always linear (i.e. the higher the level of impairment, the more likely to use the types of healthcare). Considering the effect of informal social capital, no significant interaction terms were found, which means that our expectations regarding our second research questions cannot be confirmed. However, we did find that informal social capital has a negative effect on the likelihood of using SSA-care and psychological care.

Table 5.3. *Results chronic illness on psychological care.*

	Model 1				Model 2				Model 3				Model 4			
	OR	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**	
Chronic illness (ref=chronic illness but no impairment)																
- slight impairment	2,042*	0,708	1,035	4,028	2,781**	1,033	1,343	5,761	2,758**	1,035	1,322	5,753	11,222	16,227	0,660	190,939
- moderate impairment	1,953*	0,655	1,012	3,769	2,512*	0,912	1,233	5,117	2,322*	0,852	1,132	4,766	7,032	9,878	0,448	110,336
- severe impairment	2,406*	0,992	1,072	5,400	3,091*	1,386	1,284	7,445	2,641*	1,206	1,079	6,464	15,633	23,420	0,830	294,603
Moderators/mediators																
Social capital									0,713*	0,097	0,547	0,930	0,989	0,312	0,533	1,835
x slight impairment													0,670	0,263	0,310	1,447
x moderate impairment													0,731	0,283	0,342	1,561
x severe impairment													0,580	0,254	0,246	1,370
Control variables																
Gender (ref=male)					1,590	0,419	0,949	2,664	1,684	0,449	0,999	2,838	1,693*	0,453	1,002	2,861
Age					0,950***	0,009	0,932	0,968	0,953***	0,009	0,935	0,971	0,952***	0,009	0,934	0,970
Income (ref=below average)					0,804	0,239	0,449	1,440	0,852	0,255	0,474	1,530	0,863	0,260	0,478	1,556
Education (ref=high)																
- middle					0,936	0,275	0,526	1,664	0,947	0,280	0,531	1,690	0,922	0,274	0,515	1,650
-low					0,694	0,264	0,329	1,463	0,738	0,282	0,349	1,561	0,737	0,283	0,348	1,563
Household composition (ref=single-person household)					0,717	0,214	0,400	1,286	0,825	0,252	0,454	1,500	0,824	0,252	0,452	1,501
Church attendance (ref=never)																
- less than once a month					1,478	0,776	0,528	4,138	1,374	0,736	0,481	3,928	1,390	0,750	0,483	4,001
- once a month or more					1,395	0,791	0,460	4,236	1,296	0,736	0,426	3,944	1,302	0,740	0,428	3,967
- once a week or more					0,319	0,196	0,096	1,061	0,348	0,213	0,104	1,157	0,350	0,215	0,105	1,167
Urbanization																
- Little					0,578	0,338	0,184	1,821	0,595	0,350	0,188	1,883	0,599	0,353	0,189	1,901
- Moderate					1,362	0,770	0,450	4,123	1,467	0,831	0,483	4,455	1,489	0,845	0,490	4,526
- Strong					1,250	0,665	0,440	3,548	1,294	0,691	0,455	3,685	1,286	0,690	0,449	3,680
- Very strong					1,974	1,107	0,657	5,927	1,940	1,090	0,645	5,836	1,978	1,114	0,655	5,968
Intercept	0,057***				1,300				2,987				1,005			
Log likelihood	-269,201				-240,715				-237,585				-236,723			

Source: Nivel 2018. *p<0.05; **p<0.01; ***p<0.001.

Table 5.4. *Results chronic illness on GP care.*

	Model 1				**Model 2**				**Model 3**				**Model 4**			
	OR	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**	
Chronic illness (ref=chronic illness but no impairment)																
- slight impairment	2,315**	0,708	1,272	4,214	2,021*	0,648	1,078	3,789	2,018*	0,648	1,076	3,786	18,027	26,611	0,999	325,410
- moderate impairment	5,700***	2,168	2,704	12,012	4,617***	1,822	2,131	10,005	4,594***	1,827	2,107	10,018	6,464	9,831	0,328	127,363
- severe impairment	3,338*	1,637	1,276	8,731	2,645	1,353	0,971	7,207	2,628	1,355	0,956	7,220	4,897	8,306	0,176	135,991
Moderators/mediators																
Social capital									0,985	0,151	0,729	1,331	1,168	0,246	0,773	1,764
x slight impairment													0,558	0,210	0,266	1,167
x moderate impairment													0,918	0,398	0,393	2,146
x severe impairment													0,844	0,410	0,326	2,187
Control variables																
Gender (ref=male)					0,973	0,261	0,575	1,647	0,977	0,265	0,574	1,664	0,957	0,262	0,560	1,635
Age					1,026*	0,011	1,005	1,047	1,026*	0,011	1,005	1,048	1,025*	0,011	1,004	1,047
Income (ref=below average)					0,624	0,206	0,327	1,192	0,625	0,206	0,327	1,193	0,630	0,209	0,328	1,207
Education (ref=high)																
- middle					1,428	0,443	0,778	2,621	1,430	0,443	0,778	2,626	1,418	0,442	0,770	2,612
-low					1,171	0,451	0,550	2,493	1,173	0,453	0,550	2,500	1,176	0,457	0,550	2,518
Household composition (ref=single-person household)					2,058*	0,656	1,102	3,846	2,073*	0,679	1,091	3,940	2,084*	0,684	1,095	3,967

***Table 5.4**. (continued)*

	Model 1				Model 2				Model 3				Model 4			
	OR	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**	
Church attendance (ref=never)																
- less than once a month					0,926	0,590	0,266	3,225	0,926	0,590	0,266	3,225	0,941	0,600	0,270	3,283
- once a month or more					0,875	0,494	0,289	2,648	0,877	0,496	0,290	2,655	0,888	0,505	0,291	2,708
- once a week or more					3,858	2,850	0,907	16,412	3,863	2,854	0,908	16,436	3,923	2,903	0,920	16,728
Urbanization																
- Little					0,872	0,433	0,330	2,307	0,872	0,433	0,330	2,308	0,915	0,456	0,345	2,428
- Moderate					1,692	1,010	0,525	5,451	1,695	1,012	0,526	5,461	1,802	1,082	0,555	5,846
- Strong					1,369	0,719	0,489	3,833	1,370	0,720	0,489	3,837	1,416	0,748	0,503	3,987
- Very strong					1,117	0,747	0,301	4,145	1,115	0,746	0,300	4,139	1,190	0,802	0,317	4,458
Km to GP					0,616	0,271	0,260	1,460	0,616	0,271	0,260	1,460	0,621	0,274	0,261	1,474
Intercept	5,692***				1,069				1,107				0,597			
Log likelihood	-231,834				-218,918				-218,913				-217,621			

Source: Nivel 2018. *p<0.05; **p<0.01; ***p<0.001.

Table 5.5. *Results chronic illness on paramedical care.*

	Model 1				**Model 2**				**Model 3**				**Model 4**			
	OR	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**	
Chronic illness (ref=chronic illness but no impairment)																
- slight impairment	1,792**	0,337	1,239	2,592	1,932**	0,388	1,303	2,865	1,948**	0,392	1,313	2,891	2,845	2,453	0,525	15,413
- moderate impairment	2,109***	0,381	1,480	3,005	2,432***	0,478	1,655	3,574	2,505***	0,496	1,699	3,694	2,393	1,854	0,524	10,924
- severe impairment	2,291**	0,601	1,369	3,832	3,141***	0,887	1,806	5,463	3,313***	0,950	1,889	5,812	1,230	1,131	0,203	7,458
Moderators/mediators																
Social capital									1,111	0,093	0,942	1,309	1,084	0,162	0,809	1,452
x slight impairment													0,902	0,204	0,579	1,404
x moderate impairment													1,011	0,211	0,672	1,521
x severe impairment													1,363	0,360	0,813	2,288
Control variables																
Gender (ref=male)					2,079***	0,320	1,537	2,811	2,034***	0,315	1,501	2,756	2,032***	0,316	1,499	2,756
Age					0,995	0,007	0,982	1,008	0,994	0,007	0,981	1,007	0,994	0,007	0,981	1,008
Income (ref=below average)					1,614**	0,293	1,131	2,304	1,605**	0,291	1,125	2,291	1,590*	0,290	1,113	2,272
Education (ref=high)																
- middle					0,846	0,164	0,579	1,235	0,840	0,163	0,575	1,228	0,846	0,164	0,578	1,236
-low					0,467**	0,106	0,300	0,728	0,459**	0,104	0,294	0,715	0,456**	0,104	0,292	0,712
Household composition (ref=single-person household)					0,963	0,182	0,664	1,395	0,926	0,178	0,636	1,349	0,928	0,178	0,637	1,352
Church attendance (ref=never)																
- less than once a month					1,545	0,602	0,720	3,317	1,572	0,613	0,732	3,376	1,556	0,608	0,723	3,348
- once a month or more					1,310	0,477	0,641	2,676	1,322	0,482	0,647	2,700	1,300	0,474	0,637	2,655
- once a week or more					1,029	0,258	0,630	1,683	1,020	0,257	0,623	1,671	1,013	0,256	0,618	1,663

***Table 5.5**. (continued)*

	Model 1				Model 2				Model 3				Model 4			
	OR	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**	
Urbanization																
- Little					1,654	0,515	0,899	3,043	1,638	0,510	0,890	3,016	1,673	0,523	0,907	3,088
- Moderate					1,012	0,326	0,539	1,903	0,993	0,320	0,528	1,868	0,999	0,323	0,530	1,883
- Strong					1,295	0,393	0,715	2,347	1,278	0,388	0,705	2,317	1,303	0,397	0,717	2,369
- Very strong					1,476	0,511	0,749	2,911	1,488	0,516	0,754	2,935	1,494	0,519	0,756	2,952
Intercept	1,310*				0,896				0,672				0,720			
Log likelihood	-556,038				-522,996				-522,217				-521,041			

Source: Nivel 2018. *p<0.05; **p<0.01; ***p<0.001.

Table 5.6. *Results chronic illness on care provided by medical specialists.*

	Model 1				**Model 2**				**Model 3**				**Model 4**			
	OR	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**		**OR**	**S.E.**	**95% C.I.**	
Chronic illness (ref=chronic illness but no impairment)																
- slight impairment	1,867**	0,379	1,254	2,778	1,766**	0,372	1,169	2,668	1,782**	0,376	1,178	2,694	5,970	5,503	0,980	36,360
- moderate impairment	3,338***	0,710	2,200	5,063	3,262***	0,731	2,103	5,061	3,365***	0,762	2,159	5,245	2,995	2,602	0,546	16,441
- severe impairment	4,737***	1,695	2,349	9,552	4,768***	1,759	2,314	9,826	5,044***	1,885	2,425	10,492	2,330	2,518	0,280	19,373
Moderators/mediators																
Social capital									1,112	0,107	0,921	1,343	1,166	0,177	0,867	1,569
x slight impairment													0,721	0,173	0,451	1,154
x moderate impairment													1,039	0,248	0,650	1,660
x severe impairment													1,307	0,434	0,682	2,504
Control variables																
Gender (ref=male)					0,891	0,155	0,633	1,254	0,868	0,153	0,615	1,227	0,862	0,152	0,609	1,218
Age					1,007	0,007	0,993	1,022	1,006	0,007	0,992	1,021	1,006	0,007	0,992	1,021
Income (ref=below average)					1,249	0,253	0,840	1,858	1,244	0,252	0,836	1,849	1,241	0,252	0,833	1,849
Education (ref=high)																
- middle					1,202	0,247	0,803	1,799	1,195	0,246	0,798	1,789	1,202	0,248	0,802	1,801
-low					1,116	0,281	0,681	1,828	1,099	0,277	0,670	1,802	1,101	0,279	0,670	1,809
Household composition (ref=single-person household)					0,881	0,190	0,578	1,344	0,842	0,185	0,548	1,295	0,846	0,186	0,550	1,302
Church attendance (ref=never)																
- less than once a month					1,526	0,663	0,651	3,577	1,548	0,673	0,660	3,629	1,556	0,678	0,663	3,654
- once a month or more					1,908	0,875	0,776	4,689	1,926	0,883	0,784	4,731	1,904	0,874	0,774	4,680
- once a week or more					1,449	0,433	0,807	2,602	1,441	0,431	0,802	2,590	1,436	0,431	0,797	2,588
Urbanization																
- Little					0,659	0,308	0,264	1,649	0,651	0,305	0,259	1,632	0,643	0,303	0,255	1,620
- Moderate					0,907	0,560	0,270	3,043	0,888	0,551	0,263	2,997	0,846	0,529	0,249	2,879
- Strong					0,651	0,385	0,205	2,072	0,639	0,379	0,200	2,043	0,613	0,366	0,190	1,973
- Very strong					0,590	0,371	0,172	2,022	0,591	0,373	0,172	2,035	0,569	0,361	0,164	1,972
Km to hospital					0,975	0,035	0,910	1,046	0,975	0,035	0,909	1,046	0,971	0,035	0,905	1,042
Intercept	1,900***				1,665				1,283				1,130			
Log likelihood	-447,407				-440,796				-440,192				-438,321			

Source: Nivel 2018. *p<0.05; **p<0.01; ***p<0.001.

This shows that informal social capital does play a role in the likelihood to use some types of care, but that the effect is not different for people with different levels of impairment as we expected.

***Table 5.7**. Summary of results.*

	Level of impairment ->healthcare utilization	**Direct effect of informal social capital**	**Moderating effect of informal social capital**
SSA-care	🟨	⬛	🟧
HIA care: Psychological care	🟨	🟨	🟧
HIA care: GP	🟨	🟧	🟧
HIA care: Medical specialist	⬛	🟧	🟧
HIA care: Paramedical care	⬛	🟧	🟧

⬛ Significant effects, completely as expected
🟨 Significant effects, but pattern or direction not (completely) as expected
🟧 No significant effect

5.4 Discussion and conclusion

Research has been carried out on the determinants of healthcare utilization, but research that takes into account different types of healthcare and the possible moderating relationship with informal social capital in the Netherlands is scarce. In this research we build on the existing literature by inspecting (firstly) to what extent the level of physical impairment of people with a chronic condition is related to healthcare utilization, and (secondly) how this relationship differs considering informal social capital for different types of healthcare utilization. The Dutch healthcare system provides a relevant context to test hypotheses on this, given the distinction between healthcare regulated by the Social Support Act ('SSA-care') and healthcare governed by the Health Insurance Act ('HIA-care', i.e. care supplied by psychologists, GPs, medical specialists and paramedics). We expected that the level of impairment increases the likelihood to use all types of care, but that SSA-care can be partly covered by the informal social capital of people with a chronic condition (and impairment), lessening the need to use *SSA-care.* While for the HIA types of care, we expected that informal social capital can promote healthcare utilization by practical support (i.e. knowledge about healthcare providers/healthcare system or help with transportation to healthcare services), possibly amplifying the relationship between level of impairment and healthcare utilization.

We used data from the National Panel of people with Chronic illness or Disabilities (NPCD), a nation-wide panel in the Netherlands, on which logistic regression analyses were conducted.

Our first finding confirmed what has been found earlier: people who have a chronic condition and (a certain level of) physical impairment are more likely to use different kinds of care. Differences between type of health care are significant and meaningful in this, as our results show. For HIA-care provided by medical and paramedical specialists, the level of the physical impairment clearly increases the likelihood to use these types of care. For the other types of care (SSA-care, GP and psychological care), the linearity of this relationship is less clear. An explanation for these findings can be found in the nature of the type of care. In the Netherlands, the GP is the first professional contact that patients have when they have a physical or psychological complaint. Most people in this research (93%) had at least one contact with a GP in the year prior to filling in the questionnaire. The use of paramedical care is for the most part aimed at learning to improve or cope with a physical impairment. Medical specialists as another type of health care providers, mainly diagnose and monitor (chronic) conditions. Having a chronic condition is related to having a physical impairment, so possibly people with a more severe physical impairment also have one or more chronic conditions that need more intensive monitoring.

When it comes to the role of informal social capital, we found that informal social capital is negatively related to the likelihood of using SSA-care, showing that the more people with a chronic condition (and physical impairment) are in contact with friends, family, neighbors and/or colleagues, the less likely they are to rely on the municipality for support with, for example, daily tasks. However, we did not find a *moderating* effect, that would indicate that the relationship between level of physical impairment and use of SSA-care is different for people who have a chronic condition (and impairment) with less or more informal social capital. We found a similar effect of informal social capital for one type of HIA-care, namely psychological care. Informal social capital reduces the likelihood to use psychological care as such, but again no *moderating* effects were found. An explanation for this could be the strong positive relationship between social capital and psychological health as found in other research (Pollack and von dem Knesebeck 2004; Da Silva et al. 2007; Forsman et al. 2012). For the other types of care, no significant effects of informal social capital were found.

Although having a chronic condition or physical impairment is an important determinant of healthcare utilization, several background characteristics also play a role, such as income and the level of education. People with higher income use less SSA care, which could be explained by the fact that they are able to pay for cleaning services themselves and do not need assistance of the municipality. Furthermore, people with a low educational level have a smaller likelihood to visit a paramedical specialist than people with a high educational level. Also, people with an above average income are more likely to use paramedical care. Paramedical care in the Netherlands is not completely covered by basic insurance within the HIA, which can explain these findings.

Our finding that informal social capital is negatively related to SSA-care is a policy relevant outcome. It is one of the aims of the Social Support Act (SSA) that people should rely on their own network first before asking and receiving formal support from the municipality. This support includes, amongst others, daily chores, cleaning or preparing meals. Our findings are in line with prior research from Berker and colleagues (2021) who found that support from neighbors is negatively related to receiving support from the municipality. Still, our analyses also show for people with chronic conditions, their level of physical impairment remains a constant and key factor in the utilization of healthcare. While their informal social capital is negatively related to the chance to use SSA-care and psychological care, we found no evidence that it changes the likelihood to use other types of HIA-care (GP, medical specialist or paramedical specialist), nor does informal social capital reduces the effect of physical impairment on healthcare usage of the people with a chronic condition.

REFERENCES

References

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: does it matter? *Journal of Health and Social Behavior*, *36*(1), 1-10.

Arts, W. & Gelissen, J. (2002). Three worlds of welfare capitalism or more? A state-of-the-art report. *Journal of European Social Policy, 12*(2), 137-158.

Van Agt, H. M., Stronks, K. & Mackenbach, J. P. (2000). Chronic illness and poverty in the Netherlands. *The European Journal of Public Health*, 10(3), 197-200.

Almgren, G., Magarati, M., & Mogford, L. (2009). Examining the influences of gender, race, ethnicity, and social capital on the subjective health of adolescents. *Journal of Adolescence*, *32*(1), 109-133.

Bambra, C. & Eikemo, T. (2008). Welfare state regimes, unemployment and health: a comparative study of the relationship between unemployment and self-reported health in 23 European countries. *Journal of Epidemiology and Community Health, 63(*2), 92-98.

Benjamins, M. R., & Brown, C. (2004). Religion and preventative health care utilization among the elderly. *Social Science & Medicine*, *58*(1), 109-118.

Benjamins, M. R. (2006). Religious influences on preventive health care use in a nationally representative sample of middle-age women. *Journal of Behavioral Medicine*, *29*(1), 1-16.

Berkers, E., Cloïn, M., & Pop, I. (2021). Informal help in a local setting: The Dutch Social Support Act in practice. *Health Policy*, *125*(1), 47-53.

Berkman, L.F. & Kawachi, I. (2000) *Social Epidemiology*, New York: Oxford University Press.

Bernell S. & Howard S.W. (2016). Use Your Words Carefully: What Is a Chronic Disease? *Front Public Health*, 2(4), 159. doi: 10.3389/fpubh.2016.00159. PMID: 27532034; PMCID: PMC4969287.

Beullens, K., Matsuo, H., Loosveldt, G., & Vandenplas, C. (2014). Quality report for the European Social Survey, round 6. *London: European Social Survey ERIC*.

Birk, J.L., Kronish, I.M., Moise, N., Falzon, L., Yoon, S. & Davidson, K.W. (2019). Depression and multimorbidity: Considering temporal characteristics of the associations between depression and multiple chronic diseases.*Health Psychology, 38(*9), 802.

Bolin, K., Lindgren, B. & Lundborg, P. (2008). Informal and formal care among single-living elderly in Europe. *Health Economics*, *17*(3), 393-409.

Bonoli, G. (1997). Classifying Welfare States: a Two Dimensional Approach. *Journal of Social Policy, 26*(3), 351-372.

Boogers, M., Lucardie, P., Voerman, G. (2007). *Lokale politieke groeperingen. Belangenbehartiging, protest en lokalisme*. Groningen/Tilburg: Rijksuniversiteit Groningen/Universiteit van Tilburg.

Bourdieu, P. (1986). The forms of capital. In J.G. Richardson (Ed.), *Handbook of theory and research for the sociology of education.* New York: Greenwood: 241-258.

Brabers, A., Reitsma-Van Rooijen, M. & De Jong, J. (2015). Consumentenpanel Gezondheidszorg: Basisrapport met informatie over het panel. Utrecht: NIVEL.

Brabers A. (2018). *Patient involvement and medical practice variation*. [Dissertation. Maastricht University].

Brabers, A.E.M. & de Jong, J.D. (2022). Nivel Consumentenpanel Gezondheidszorg : basisrapport met informatie over het panel 2022. Utrecht: Nivel.

Broemeling, A. M., Watson, D. E., & Prebtani, F. (2008). Population patterns of chronic health conditions, co-morbidity and healthcare use in Canada: implications for policy and practice. *Healthcare Quarterly*, *11*(3), 70-76.

Burns, A., Leavey, G., Ward, M., & O'Sullivan, R. (2020). The impact of loneliness on healthcare use in older people: evidence from a nationally representative cohort. *Journal of Public Health*, 30, 675-684.

Busse, R., Blümel, M., Scheller-Kreinsen, D. & Zentner, A. (2010) *Tackling chronic disease in Europe: strategies, interventions and challenges*, Copenhagen: WHO Regional Office Europe. Nivel (2020). Nivel Dutch Healthcare Consumer Panel. https://www.nivel.nl/en/dutch-health-care-consumer-panel

Catassi, C., Elli, L., Bonaz, B., Bouma, G., Carroccio, A., Castillejo, G. & Dieterich, W. (2015). Diagnosis of non-celiac gluten sensitivity (NCGS): the Salerno Experts' Criteria. *Nutrients*, *7*(6), 4966-4977.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, *5*(2), 168-195.

Ciacci, C., Iavarone, A., Siniscalchi, M., Romano, R. & De Rosa, A. (2002). Psychological dimensions of celiac disease: toward an integrated approach. *Digestive diseases and sciences*, *47*(9), 2082-2087.

Cohen, S. (2004). Social relationships and health. *American Psychologist*, *59(*8), 676.

Cornwell, E. Y. & Waite, L. J. (2009). Social disconnectedness, perceived isolation, and health among older adults. *Journal of Health and Social Behavior*, *50*(1), 31-48.

Cutler, D. M. & Lleras-Muney, A. (2006). *Education and health: evaluating theories and evidence.* Cambridge, MA: National Bureau of Economic Research.

Chabrol, H., Montovany, A., Chouicha, K. & Duconge, E. (2001). Study of the CES-D on a sample of 1,953 adolescent students. *L'encéphale*, *28*(5), 429-432.

Da Silva, M. J., Huttly, S. R., Harpham, T., & Kenward, M. G. (2007). Social capital and mental health: A comparative analysis of four low-income countries. *Social Science & Medicine*, 64(1), 5-20.

Deri, C. (2005). Social networks and health service utilization. *Journal of Health Economics*, *24*(6), 1076-1107.

DeJean, D., Giacomini, M., Vanstone, M., & Brundisini, F. (2013). Patient experiences of depression and anxiety with chronic disease: a systematic review and qualitative meta-synthesis. *Ontario Health Technology Assessment Series*, *13*(16), 1.

De Klerk, M., Iedema, J., & van Campen, C. (2006). SCP-maat voor lichamelijke beperkingen op basis van AVO 2003. Den Haag: Sociaal en Cultureel Planbureau.

Dewar, D. H., Donnelly, S. C., McLaughlin, S. D., Johnson, M. W., Ellis, H. J., & Ciclitira, P. J. (2012). Management of persistent symptoms in patients on a gluten-free diet. *World Gastroenterology*, 18(12), 1348-1356.

Dutch Association of Gastroenterologists. (2008). Richtlijn Coeliakie en Dermatitis Herpetiformis. Retrieved September 15, 2015, from http://www.mdl.nl/uploads/240/442/richtlijn_Coeliakie_definitief.pdf

Dutch Celiac Association. (2008). Coeliakie? Retrieved September 15, 2015, from http://www.gluten-check.nl/publicaties/Coeliakie-vereniging-bloedtest.pdf

Eikemo, T, A., Bambra, C., Joyce, K. & Dahl, E. (2008). Welfare state regimes and income-related health inequalities: a comparison of 23 European countries, *The European Journal of Public Health*, 18(6), 593-599.

Eikemo, T. A. (2010). The European Social Survey (ESS) and comparative health research, *Salute e Società,* 2, 95-117.

Erlinghagen, M., Knuth, M. & Knuth, P.D.D.M. (2008). Why are Germans Unemployed but other Europeans Incapacitated? IAB / DGS conference

'Activation policies on the Fringers of society', Nuerenberg, Germany, 15-16 May, 2008.

Esping-Andersen, G. (1990). *The Three Worlds of Welfare Capitalism*, Oxford: Polity Press.

European Chronic Disease Alliance (ECDA) (2015). Retrieved from: http://www.alliancechronicdiseases.org/

European Commission for Public Health (ND). Major and Chronic Diseases: Policy. Retrieved from: http://ec.europa.eu/health/major_chronic_diseases/policy/index_en.htm

Eurostat (2022). Mortality and life expectancy statistics. Retrieved from: Mortality and life expectancy statistics - Statistics Explained (europa.eu)

Fasano, A., & Catassi, C. (2001). Current approaches to diagnosis and treatment of celiac disease: An evolving spectrum. *Gastroenterology*, 120(3), 636-651.

Fasano, A. & Flaherty, S. (2014). *Gluten Freedom.* New York: Turner Publishing Company.

Faulkner-Hogg, K. B., Selby, W. S., & Loblay, R. H. (1999). Dietary analysis in symptomatic patients with coeliac disease on a gluten-free diet: the role of trace amounts of gluten and non-gluten food intolerances. *Scandinavian Journal of Gastroenterology, 34*(8), 784-789.

Fenger, M. (2007). Welfare regimes in Central and Eastern Europe: Incorporating post-communist countries in a welfare regime typology. *Contemporary Issues and Ideas in Social Sciences*, *3(*2), 1-30.

Ferlander, S. (2007). The importance of different forms of social capital for health. *Acta Sociologica*, *50*(2), 115-128.

Ferrera, M. (1996). The 'Southern model' of welfare in social Europe. *Journal of European Social Policy,* 6, 17-37

Fjær, E. L., Balaj, M., Stornes, P., Todd, A., McNamara, C. L., & Eikemo, T. A. (2017). Exploring the differences in general practitioner and health care specialist utilization according to education, occupation, income and social networks across Europe: findings from the European social survey (2014) special module on the social determinants of health. *European Journal of Public Health*, *27*(1), 73-81.

Fortin, M., Bravo, G., Hudon, C., Lapointe, L., Almirall, J., Dubois, M. F., & Vanasse, A. (2006). Relationship between multimorbidity and health-related quality of life of patients in primary care. *Quality of Life Research*, *15*(1), 83-91.

Forsman, A. K., Nyqvist, F., Schierenbeck, I., Gustafson, Y., & Wahlbeck, K. (2012). Structural and cognitive social capital and depression among older adults in two Nordic regions. *Aging & Mental Health*, *16*(6), 771-779.

Fougeyrollas, L. N. P. (2000) Long-term consequences of spinal cord injury on social participation: the occurrence of handicap situations. *Disability and Rehabilitation*, *22(*4), 170-180.

Franzen, A., & Hangartner, D. (2006). Social networks and labour market outcomes: The non-monetary benefits of social capital. *European Sociological Review*, *22*(4), 353-368.

Garthwaite, K. (2015). 'Keeping meself to meself'–How Social Networks Can Influence Narratives of Stigma and Identity for Long-term Sickness Benefits Recipients. *Social Policy & Administration*, *49*(2), 199-212.

Gesthuizen, M., Van der Meer, T. & Scheepers, P. L. H. (2008). Education and dimensions of social capital: do educational effects differ due to educational expansion and social security expenditure? *European Sociological Review, 24(*5), 617–632.

Gray, A. (2009). The social capital of older people, *Ageing and Society, 29*(1), 5-31.

Green, P. H. & Jones, R. (2010). *Celiac Disease: A Hidden Epidemic*. New York: Harpercoller Publishers.

Haas, S. A., Schaefer, D. R. & Kornienko, O. (2010). Health and the structure of adolescent social Networks. *Journal of Health and Social Behavior*, *51(*4), 424-439.

Hall, N. J., Rubin, G., & Charnock, A. (2009). Systematic review: adherence to a gluten-free diet in adult patients with coeliac disease. *Alimentary Pharmacology & Therapeutics*, *30*(4), 315-330.

Halleröd, B. & Larsson, D. (2008). Poverty, welfare problems and social exclusion. *International Journal of Social Welfare,* 17(1), 15-25.

Hallert, C., Grännö, C., Grant, C., Hulten, S., Midhagen, G., Ström, M., Svensson, H., Valdimarsson, T., & Wickström, T. (1998). Quality of life of adult coeliac patients treated for 10 years. *Scandinavian Journal of Gastroenterology*, 33(9), 933-938.

Hayes (2018). Mediate. https://afhayes.com/spss-sas-and-r-macros-and-code.html (2014). Accessed 1 May 2018.

Hees, S. van, Oldenkamp, M., Putter, I. de, Hoek, L. van der, & Boeije, H. (2018). Participatiemonitor 2008-2016: Deelname aan de samenleving van mensen met een beperking en ouderen. Utrecht: Nivel.

Henning-Smith, C. E., Gonzales, G., & Shippee, T. P. (2016). Barriers to timely medical care for older adults by disability status and household composition. *Journal of Disability Policy Studies*, *27*(2), 116-127.

De Heus, P., Van der Leeden, R., & Gazendam, B. (1995). *Toegepaste data analyse: Technieken voor niet-experimenteel onderzoek in de sociale wetenschappen*. Lemma.

Higgs, S., & Ruddock, H. (2020). Social influences on eating. *Handbook of eating and drinking: Interdisciplinary Perspectives*, 277-291.

Hodgson, S., Watts, I., Fraser, S., Roderick, P., & Dambha-Miller, H. (2020). Loneliness, social isolation, cardiovascular disease and mortality: a synthesis of the literature and conceptual framework. *Journal of the Royal Society of Medicine*, *113*(5), 185-192.

Hogan, D. P., Eggebeen, D. J., & Clogg, C. C. (1993). The structure of intergenerational exchanges in American families. *The American Journal of Sociology,* 98, 1428-1458.

Hopman, P., Heins, M. J., Korevaar, J. C., Rijken, M., & Schellevis, F. G. (2016). Health care utilization of patients with multiple chronic diseases in the Netherlands: differences and underlying factors. *European Journal of Internal Medicine*, *35*, 44-50.

Huijts, T. H. M. (2011). *Social ties and health in Europe: Individual associations, cross-national variations, and contextual explanations* (Dissertation). Nijmegen: Radboud University Nijmegen.

Huijts, T. H. M. & Kraaykamp, G. (2011). Religious involvement, religious context, and self-assessed health in Europe. *Journal of Health and Social Behavior,* 52(1), 91-106.

Israel, S., & Spannagel, D. (2019). Material deprivation in the EU: a multi-level analysis on the influence of decommodification and defamilisation policies. *Acta Sociologica*, *62*(2), 152-173.

Janssen, J., & Korsten, A. F. A. (2003). De wederopstanding van lokale lijsten. Bestuurswetenschappen, 57(2), 90-112.

Jeurissen, P.P. & Maarse, J.H. (2021). The market reform in Dutch healthcare: results, lessons and prospects. European Observatory on Health Systems and Policies.

Joachim, G. & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, *32*(1), 243-248.

Kääriäinen, J. & Lehtonen, H. (2006). The variety of social capital in welfare state regimes–a comparative study of 21 countries. *European Societies*, 8(1), 27-57.

Kawachi, I., Colditz, G. A., Ascherio, A., Rimm, E. B., Giovannucci, E., Stampfer, M.J. & Willett, W. C. (1996). A prospective study of social networks in relation to total mortality and cardiovascular disease in men in the USA. *Journal of Epidemiology and Community Health*, 50(3), 245-251.

Kawachi, I., Kennedy, B. P., & Glass, R. (1999). Social capital and self-rated health: a contextual analysis. *American Journal of Public Health*, *89*(8), 1187-1193.

Kawachi, I., Subramanian, S. V. & Kim, D. (2008). Social capital and health. *Social Capital and Health*, 1-26.

Kromhout, M., Feijten, P., Voogd-Hamelink, M. D. & Echtelt, P. V. (2020). Sociaal domein op koers?. Den Haag: SCP.

Kroneman M., Boerma W., van den Berg M., Groenewegen P., de Jong J. & van Ginneken E. (2016). The Netherlands: health system review. *Health Systems in Transition, 18*(2), 1–239.

Ladwig, K. H., Marten-Mittag, B., Formanek, B., & Dammann, G. (2000). Gender differences of symptom reporting and medical health care utilization in the German population. *European Journal of Epidemiology*, *16*(6), 511-518.

Lee, A., & Newman, J. M. (2003). Celiac diet: Its impact on quality of life. *Journal of the American Dietetic Association, 103*(11), 1533-1535.

Leyland, A. H., & Groenewegen, P. P. (2020). *Multilevel modelling for public health and health services research: health in context*. Springer Nature.

Liew, H. P. (2012). Depression and chronic illness: a test of competing hypotheses. *Journal of Health Psychology*, *17*(1), 100-109.

Liang, J. (1986). Self-reported physical health among aged adults. *Journal of Gerontology*, *41*(2), 248-260.

Lin, N., Ye, X. & Ensel, W. M. (1999). Social Support and Depressed Mode: A Structural Analysis. *Journal of Health and Social Behaviour,* 40, 334–59.

Lin, N. (2000). Inequality in social capital. *Contemporary Sociology,* 785-795.

Lin, N., Cook, K. S., & Burt, R. S. (2001). *Social capital: Theory and research*. Transaction Publishers.

Lindström, M. (2009). Marital status, social capital, material conditions and self-rated health: a population-based study. *Health Policy*, 93(2), 172-179.

Loef, B., Meulman, I., Herber, G. C. M., Kommer, G. J., Koopmanschap, M. A., Kunst, A. E., Polder, J., Wong, A. & Uiters, E. (2021). Socioeconomic differences in healthcare expenditure and utilization in The Netherlands. *BMC Health Services Research*, *21*(1), 1-17.

Lohiniemi, S., Mustalahti, K., Collin, P. & Mäki, M. (1998). Measuring quality of life in coeliac disease patients. Changing Features of Coeliac Disease. Tampere: Finnish Coeliac Society, 71-77.

Lub, V. & Uyterlinde, M. (2012). Evaluating State-promoted Civic Engagement and Participation of Vulnerable Groups: The Paradoxical Policies of the Social Support Act in the Netherlands. *Journal of Social Policies, 41*(2), 373-390.

Maarse, J. H. & Jeurissen, P. P. (2016). The policy and politics of the 2015 long-term care reform in the Netherlands. *Health Policy*, *120*(3), 241-245.

McNallan, S. M., Singh, M., Chamberlain, A. M., Kane, R. L., Dunlay, S. M., Redfield, M. M., Weston, S.A. & Roger, V. L. (2013). Frailty and healthcare utilization among patients with heart failure in the community. *JACC: Heart Failure*, *1*(2), 135-141.

Menting, J., Schelven, F. van, Grosscurt, R., Spreeuwenberg, P. & Heijmans, M. (2019). Zorgmonitor 2019: Ontwikkelingen in de zorg voor mensen met een chronische ziekte: 2005-2018. Utrecht: Nivel.

van Middendorp, J. G. (2022). *" Als de financiën op orde zijn, heb je meer rust": Ondersteuning aan cliënten met financiële problemen door vrijwilligers* (Dissertation). Nijmegen: Radboud University Nijmegen.

Ministry of Health, Welfare and Sport (2001). Vraag aan bod: hoofdlijnen van vernieuwing van het zorgstelsel [Giving demand a chance: headlines of reform of the health care system]. The Hague: Ministry of Health, Welfare and Sport.

Moussavi, S., Chatterji, S., Verdes, E., Tandon, A., Patel, V. & Ustun, B. (2007). Depression, chronic diseases, and decrements in health: results from the World Health Surveys. *The Lancet,* 370, 9590, 851-858.

Mustalahti, K., Lohiniemi, S., Collin, P., Vuolteenaho, N., Laippala, P. & Maki, M. (2002). Gluten-free diet and quality of life in patients with screen-detected celiac disease. *Effective Clinical Practice*, *5*(3), 105-113, 2002.

Nachman, F., Maurino, E., Vazquez, H., Sfoggia, C., Gonzalez, A., Gonzalez, V., Plancer del Campo, M., Smecuol, E., Niveloni, S., Sugai. E., Mazure, R., Cabanne, A. & Bai, J. C. (2009). Quality of life in celiac disease patients: prospective analysis on the importance of clinical severity at diagnosis and the impact of treatment, *Digestive and Liver Disease*, 41(1), 15-25, 2009.

National Institute for Public Health and Environment (2020). Trendscenario: ziekten en aandoeningen. Retrieved from: https://www.volksgezondheidtoekomstverkenning.nl/c-vtv/trendscenario-update-2020/ziekten-aandoeningen

National Institute for Public Health and Environment (2018). Aantal mensen met chronische ziekte bekend bij de huisarts. Retrieved from: https://www.volksgezondheidenzorg.info/onderwerp/chronische-ziekten-en-multimorbiditeit/cijfers- context/huidige-situatie#node-aantal-mensen-met-chronische-aandoening-bekend-bij-de-huisarts

National Institute for Public Health and Environment (2022). Chronische aandoeningen en multimorbiditeit: Leeftijd en geslacht. Retrieved from: Chronische aandoeningen en multimorbiditeit | Leeftijd en geslacht | Volksgezondheid en Zorg (vzinfo.nl)

Newall, J., N. & McArthur, V.H.M., (2014). A longitudinal examination of social participation, loneliness, and use of physician and hospital services. *Journal of Aging and Health*, *27* (2014), pp. 500-518.K.

Nivel (2020). National Panel of the Chronically ill and Disabled. https://www.nivel.nl/en/national-panel-chronically-ill-and-disabled-npcd

Nivel (2020). Dutch Healthcare Consumer Panel. https://www.nivel.nl/en/dutch-health-care-consumer-panel

OECD/European Observatory on Health Systems and Policies (2021), The Netherlands: Country Health Profile 2021, State of Health in the EU, OECD Publishing, Paris/European Observatory on Health Systems and Policies, Brussels.

Ohrnberger, J., Fichera, E., & Sutton, M. (2017). The relationship between physical and mental health: A mediation analysis. *Social Science & Medicine*, *195*, 42-49.

Oldenkamp, M., de Klerk, M. & Wagemakers, A. (2013). Beperkt contact?. *Tijdschrift voor Gezondheidswetenschappen*, *91*(8), 478-488.

Olsson, C., Lyon, P., Hörnell, A., Ivarsson, A., & Sydner, Y. M. (2009). Food that makes you different: the stigma experienced by adolescents with celiac disease. *Qualitative Health Research*, *19*(7), 976-984, 2009.

Ooms I., Sadiraj K. & Pommer E.(2017). Regionale verschillen in het sociaal domein: voorzieningengebruik nader verklaard. Den Haag: Sociaal en Cultureel Planbureau.

Van Oorschot, W., Arts, W. & Gelissen, J. (2006). Social capital in Europe: Measurement and social and regional distribution of a multifaceted phenomenon. *Acta Sociologica,* 49(2), 149-167.

Van Oorschot, W., & Finsveen, E. (2010). Does the welfare state reduce inequalities in people's social capital? *International Journal of Sociology and Social Policy*.

Van Oostrom, S. H., Picavet, H. S. J., De Bruin, S. R., Stirbu, I., Korevaar, J. C., Schellevis, F. G. & Baan, C. A. (2014). Multimorbidity of chronic diseases and health care utilization in general practice. *BMC Family Practice*, *15*(1), 1-9.

Open data van de overheid https://data.overheid.nl/datasets?facet_theme%5B0%5D=http%3A//standaarden.overheid.nl/owms/terms/Bestuur

Patten S.B. (2001). Long-term medical conditions and major depression in a Canadian population study at waves 1 and 2. *Journal of Affective Disorders, 28*(4), 148–54.

Paugam, S. (1996). Poverty and social disqualification: A comparative analysis of cumulative disadvantage in Europe. *Journal of European Social Policy,* 6(4), 287-303.

Pichler, F. & Wallace, C. (2007). Patterns of formal and informal social capital in Europe. *European Sociological Review*, 23*(*4), 423–436.

Pinkhasov, R. M., Wong, J., Kashanian, J., Lee, M., Samadi, D. B., Pinkhasov, M. M., & Shabsigh, R. (2010). Are men shortchanged on health? Perspective on health care utilization and health risk behavior in men and women in the United States. *International Journal of Clinical Practice*, *64*(4), 475-487.

Pinquart, M. (2001). Correlates of subjective health in older adults: a meta-analysis. *Psychology and Aging,* 16(3), 414.

Pollack, C. E. & von dem Knesebeck, O. (2004). Social capital and health among the aged: comparisons between the United States and Germany. *Health and Place,* 10(4), 383-391.

Portela, M., Neira, I. & del Mar Salinas-Jiménez, M. (2013). Social capital and subjective wellbeing in Europe: A new approach on social capital. *Social Indicators Research, 114*(2), 493-511.

Portes, A. (1998). Social capital: Its origins and applications in modern sociology. *Annual Review of Sociology*, *24*(1), 1-24.

Preacher, K. J. & Hayes, A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods, 40(*3), 879-891.

Putnam, R. D., (2000). *Bowling Alone: the Collapse and Revival of American Community*. New York: Simon and Schuster.

Rodgers, J., Valuev, A.V., Hswen, Y. & Subramanian, S.V. (2019). Social capital and physical health: An updated review of the literature for 2007–2018. *Social Science & Medicine*, 236, 112360.

Rodríguez-Pose, A., & Von Berlepsch, V. (2014). Social capital and individual happiness in Europe. *Journal of Happiness Studies*, *15*(2), 357-386.

Rosén, A., Ivarsson, A., Nordyke, K., Karlsson, E., Carlsson, A., Danielsson, L., Högberg, L. & Emmelin, M. (2011). Balancing health benefits and social sacrifices: A qualitative study of how screening-detected celiac disease impacts adolescents' quality of life. *BMC Pediatrics, 11*(1), 32.

Savelkoul, M., Gesthuizen, M. & Scheepers, P. L.H. (2011). Explaining relationships between ethnic diversity and informal social capital across European countries and regions: Tests of constrict, conflict and contact theory. *Social Science Research, 40*(4), 1091–1107.

Scheepers, P. L.H., Te Grotenhuis, M. & Gelissen, J. (2002). Welfare states and dimensions of social capital: Cross-national comparisons of social contacts in European countries. *European Societies,* 4,(2), 185-207.

Shafer, A. B. (2006). Meta-analysis of the factor structures of four depression questionnaires: Beck, CES-D, Hamilton, and Zung. *Journal of Clinical Psychology, 62*(1), 123-146.

Simon-Tuval, T., Scharf, S. M., Maimon, N., Bernhard-Scharf, B. J., Reuveni, H. & Tarasiuk, A. (2011). Determinants of elevated healthcare utilization in patients with COPD. *Respiratory Research*, *12*(1), 1-8.

Smith, D. F., & Gerdes, L. U. (2012). Meta-analysis on anxiety and depression in adult celiac disease. *Acta Psychiatrica Scandinavica, 125*(3), 189-193.

Smith, K.P. & Christakis, N.A. (2008). Social Networks and Health. *Annual Sociological Review*, 34, 405-429.

Snijders, T. A. B., & Bosker, R. J. (2012). *Multilevel analysis: An introduction to basic and advanced multilevel modeling*. Sage.

StataCorp. Stata statistical software: release 15. College Station, TX: StataCorp LLC; 2017.

Sverker, A., Östlund, G., Hallert, C., & Hensing, G. (2009). "'I lose all these hours…'–exploring gender and consequences of dilemmas experienced in everyday life with coeliac disease." *Scandinavian Journal of Caring Sciences*, *23*(2), 342-352.

The World Bank (2011). Data: Health Expenditure, total (% GDP). Retrieved from: http://data.worldbank.org/indicator/SH.XPD.TOTL.ZS/countries

Tijhuis, M.A., Flap, H.D., Foets, M. & Groenewegen, P.P. (1998). Selection in the social network: Effects of chronic diseases. *The European Journal of Public Health*, *8*(4), 286-293.

Tigges, L. M., Browne, I. & Green, G. P. (1998). Social isolation of the urban poor. *The Sociological Quarterly*, *39(*1), 53-77.

Trifiletti, R. (1999). Southern European welfare regimes and the worsening position of women. *Journal of European Social Policy, 9(*1), 49-64.

UNESCO (2015). ISCED: International Standard Classification of Education. Retrieved from: http://www.uis.unesco.org/Education/Pages/international-standard-classification-of-education.aspx

United Nations (2022). Chapter IV Human Rights - 15. Convention on the Rights of Persons with Disabilities - Status as at 25-05-2022. Geraadpleegd op 25 mei 2022.

United Nations (2008). Conventions of the rights of persons with disabilities. Retrieved from: https://treaties.un.org/doc/Publication/CTC/Ch_IV_15.pdf

Vermeij, L. & Hamelink, W. (2021). *Lang niet toegankelijk. Ervaringen van Nederlanders met een lichamelijke beperking als spiegel van de samenleving*. Den Haag: SCP.

Visser, M., Gesthuizen, M. & Scheepers, P. (2014). The impact of macro-economic circumstances and social protection expenditure on economic deprivation in 25 European countries, 2007-2011. *Social Indicators Research,* 115, 1179-1203.

Wahab, P. J., Meijer, J. W. & Mulder, C. J. (2002). Histologic follow-up of people with celiac disease on a gluten-free diet slow and incomplete recovery. *American Journal of Clinical Pathology, 118*(3), 459-463.

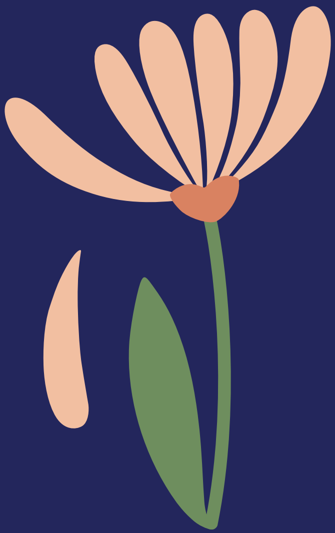
Waverijn, G., Wolfe, M. K., Mohnen, S., Rijken, M., Spreeuwenberg, P., & Groenewegen, P. (2014). A prospective analysis of the effect of neighbourhood and individual social capital on changes in self-rated health of people with chronic illness. *BMC Public Health*, *14*(1), 1-11.

Waverijn, G., Groenewegen, P.P. & de Klerk, M. (2017). Social capital, collective efficacy and the provision of social support services and amenities by municipalities in the Netherlands. *Health & Social Care in the Community, 25*(2), 414-423.

Wildeboer Schut, J., Vrooman, J. C. & De Beer, P. (2000). *De maat van de verzorgingsstaat: Inrichting en werking van het sociaal-economisch bestel in elf Westerse landen*, The Hague: Sociaal en Cultureel Planbureau.

Woolcock, M. (1998). Social capital and economic development: towards a theoretical synthesis and policy framework. *Theory and Society, 27*(2): 151–208.

APPENDICES



Appendix A (Chapter 2)

***Table A.1**. Classification Welfare Regimes.*

Welfare Regime	**Countries**
Scandinavian	Denmark, Sweden, Finland, Iceland, Norway, The Netherlands[1].
Anglo Saxon	United Kingdom, Ireland.
Bismarkian	Belgium, Germany, Switzerland, France.
Southern	Spain, Cyprus, Portugal, Italy.
Former USSR	Russian Federation, Ukraine, Estonia, Lithuania.
post-communist	Albania, Bulgaria, Czech Republic, Hungary, Poland, Slovakia, Slovenia.

[1] There has been a debate about in which regime the Netherlands should be placed. The Netherlands are sometimes refered to as an anomalie (Arts and Gelissen, 2002) because it can both be placed within the Bismarkian regime (Bambra and Eikemo, 2008) as the Scandinavian regime (Scheepers et al. 2002). It is thus more a hybrid case than a prototype of a specific ideal-type. We chose to categorize the Netherlands in the Scandinavic regime in line with Wildeboer et al. (2000). Wildeboer et al. (2000) base their decision on an analysis that includes fifty-eight characteristics in eleven welfare state regimes.

Appendix B (Chapter 3)

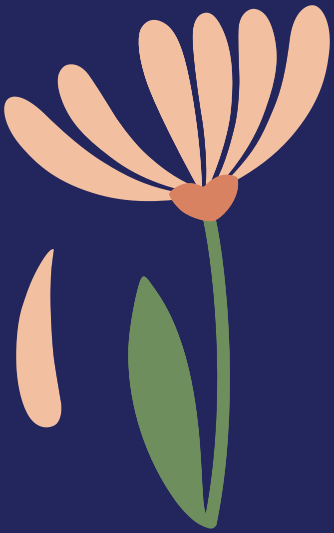
Table B.1. *Values of Omnibus test mediation analysis informal social capital.*

	Effect	**S.E.**	**LLCI**	**ULCI**
Subjective health	0.0005	0.0002	0.0001	0.0009
Depression	-0.0044	0.0017	-0.0083	-0.0020
Subjective income	0.0002	0.0005	-0.0007	0.0013

Table B.2. *Values of Omnibus test mediation analysis neighborhood participation.*

	Effect	**S.E.**	**LLCI**	**ULCI**
Subjective health	0.0002	0.0002	-0.0001	0.0005
Depression	-0.0018	0.0008	-0.0037	-0.0005
Subjective income	0.0000	0.0004	-0.0008	0.0009

VERKLARING DATAMANAGEMENT



Verklaring datamanagement

Verklaring datamanagement PhD Thesis Radboud Social Cultural Research, Radboud Universiteit

Sectie A. Primaire data/gegevens

Voor mijn thesis heb ik zelf **primaire** data/gegevens verzameld?

Ja

Ik verklaar dat		
A1.	De data / gegevens zijn verkregen met toestemming van informanten.	Ja
A2.	Privacy gevoelige data / gegevens zijn versleuteld en opgeslagen op een beveiligde computer of server.	Ja
A3.	De data / gegevens tot minimaal tien jaar na afloop van het onderzoek worden bewaard in het kader van wetenschappelijke integriteit.	Ja
A4.	Geanonimiseerde data / gegevens zijn gedeponeerd in een dataregistratiesysteem (Research Data Repository, DANS-KNAW).	Nee*
A5.	Toegang tot geanonimiseerde data / gegevens is geregeld in het kader van datamanagement (FAIR-principes).	Nee*

*zie toelichting in Bijlage bij Verklaring Datamanagement.

Sectie B. Secundaire data / gegevens

Voor mijn thesis heb ik door andere onderzoekers verzamelde informatiebronnen gebruikt?

Ja

Ik verklaar dat		
B1.	De data / gegevens op legitieme wijze zijn verkregen.	Ja
B2.	Niet publiek toegankelijke data / gegevens gedurende het onderzoek zijn opgeslagen op een beveiligde computer of server.	Ja
B3.	De data / gegevens niet zijn gedeeld met derden en is gehandeld in overeenstemming met de afspraken gemaakt met de informatieverstrekker.	Ja

Sectie C. Algemeen

Ik verklaar dat		
C1.	Een korte methodologische verantwoording, en/of de syntax en methode van databewerking is gedeponeerd in een zogenaamd ‘publication package’.	Nee*
C2.	Gegevens in publicaties niet zijn te herleiden tot een individueel persoon (m.u.v. expliciete toestemming).	Ja
C3.	De data op integere wijze zijn geanalyseerd en niet doelbewust zijn gemanipuleerd richting bepaalde uitkomsten.	Ja

*zie toelichting in Bijlage bij Verklaring Datamanagement.

Bijlage bij Verklaring datamanagement

Voor dit proefschrift zijn verschillende databronnen gebruikt die hieronder worden beschreven.

European Social Survey (hoofdstuk 2)

Voor hoofdstuk 2 is gebruik gemaakt van de European Social Survey 2012 (wave 6). Deze gegevens zijn openbaar toegankelijk.

Consumentenpanel en Panel Chronisch Zieken en Gehandicapten van het Nivel (hoofdstuk 3 en 5)

Voor het gebruik van deze gegevens moet een aanvraag gedaan worden bij de programmacommissies van deze panels. Afgesproken is, dat als het nodig is, de data opvraagbaar is bij het Nivel of de auteurs van de betreffende hoofdstukken.

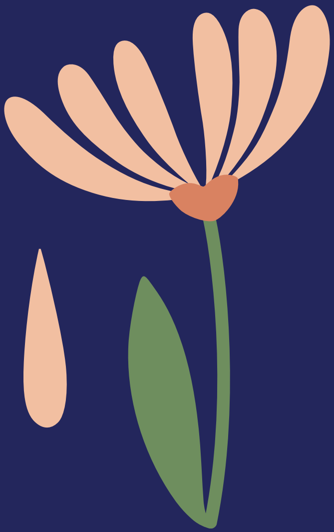
Data verzameld met behulp van de Nederlandse Coeliakie Vereniging (hoofdstuk 4)

Voor dit hoofdstuk is een enquête uitgezet onder leden van de Nederlandse Coeliakie Vereniging. Een deel van de respondenten heeft op verzoek een andere enquête doorgestuurd naar een bekende (zonder coeliakie of glutensensitiviteit). Van de respondenten en de Nederlandse Coeliakie Vereniging is geen toestemming verkregen om de onderzoeksdata voor andere onderzoeken beschikbaar te stellen. Waar nodig (bijvoorbeeld voor het repliceren van de resultaten) is de data opvraagbaar tot 15 jaar na het onderzoek.

Voor alle hoofdstukken is een publication package beschikbaar. Deze zijn niet gedeponeerd, maar opgeslagen op een beveiligde server en kunnen worden opgevraagd als dit gewenst is.

SUMMARY IN DUTCH

Nederlandse Samenvatting



Nederlandse samenvatting (summary in Dutch)

Inleiding

Met de toename van het aantal mensen dat leeft met een chronische aandoening, is er meer aandacht gekomen voor deze groep. Een belangrijk aspect hierbij is dat mensen met een chronische aandoening gelijke rechten en kansen hebben. Participatie in de maatschappij (bijvoorbeeld door het werken aan toegankelijkheid van openbare ruimten, maar ook de vrijheid hebben om het leven zo in te richten als men wil (door bijvoorbeeld te kunnen (blijven) werken)), is daarmee tegenwoordig een belangrijk beleidsthema. Tegelijkertijd stond en staat het zorgstelsel onder druk en is het een uitdaging dit houdbaar te houden. Hiertoe is met een aantal hervormingen gepoogd de zorg efficiënter en meer persoonsgericht te maken, waarbij ook participatie als belangrijk thema is opgenomen. Zo is in 2007 onder andere de Wet maatschappelijke ondersteuning (Wmo) ingevoerd en in 2015 werd deze verder uitgebreid. Hiermee hebben gemeenten de verantwoordelijkheid gekregen voor het organiseren van bepaalde zorg en ondersteuning voor hun inwoners. Een belangrijk uitgangspunt van de Wmo is het bevorderen van zelfredzaamheid van mensen met een chronische aandoening door eerst een beroep te doen op hun sociale netwerk of op vrijwilligers, en door algemene voorzieningen in te richten en hierop terug te vallen waar mogelijk. Pas als deze mogelijkheden onvoldoende blijken te zijn, biedt de gemeente meer ondersteuning (denk aan hulp in het huishouden, maaltijdservices etc.). De aanname daarbij is dat gemeenten beter zicht hebben op de ondersteuningsbehoefte van hun inwoners, gemakkelijker maatwerk kunnen leveren en zo beter de zelfredzaamheid en participatie kunnen bevorderen.

Doelstelling en hoofdvraag van dit proefschrift

Hoewel niet elke chronische aandoening of beperking dezelfde uitwerking heeft in het dagelijks leven, kan het hebben ervan een negatieve invloed hebben op verschillende aspecten van het leven, zoals op de mentale gezondheid en de kwaliteit van leven. Uit eerder onderzoek blijkt dat het hebben van een chronische aandoening of beperking ook negatief samen kan hangen met de hoeveelheid sociale relaties die men heeft. Er kunnen verschillende barrières zijn in praktische zin, maar ook in sociale zin, die sociale participatie en het hebben van sociale relaties belemmeren. Het kan bijvoorbeeld door een fysieke beperking of stigmatisering moeilijker zijn om vrienden te ontmoeten. In de context waarin juist een groter beroep wordt gedaan op de zelfredzaamheid van mensen en hun sociale netwerk, is het dus des te belangrijker om de relatie tussen het hebben van een chronische aandoening of beperking en informeel sociaal kapitaal beter te begrijpen. Dit is het hoofddoel van dit promotieonderzoek. Bij dit doel benadrukken we dat we niet de beleidswijzigingen in Nederland ‘an sich’ evalueren, maar wel ingaan op aannames achter deze beleidswijzigingen. In dit proefschrift vormt de theorie van Bourdieu over sociaal kapitaal de kapstok op grond waarvan we hypothesen afleiden. Verschillende grootschalige surveydata zijn gebruikt om deze hypothesen te toetsen.

Theoretische achtergrond van relatie tussen het hebben van een chronische aandoening en informeel sociaal kapitaal

Bourdieu definieerde als één van de eersten sociaal kapitaal als “het geheel van (bestaande of potentiële) hulpbronnen die horen bij het onderdeel zijn van een duurzaam netwerk van meer of minder geïnstitutionaliseerde relaties” en dit concept werd toegepast op verschillende domeinen zoals leefstijlen, cultuurdeelname en sociale mobiliteit. Andere wetenschappers bouwden voort op Bourdieu, bijvoorbeeld door te focussen op de homo- of heterogeniteit van het sociaal kapitaal, dat ‘bonding and bridging’ sociaal kapitaal wordt genoemd. Een andere belangrijke specificering van sociaal kapitaal in de literatuur is die van formeel en informeel sociaal kapitaal. Formeel sociaal kapitaal bestaat hier uit deelname aan meer ‘formele’, geïnstitutionaliseerde netwerken, zoals via de kerk of georganiseerd vrijwilligerswerk. Informeel sociaal kapitaal bestaat uit meer ‘informele’ of persoonlijke netwerken, zoals de relaties met vrienden en familie. In dit proefschrift focussen we op informeel sociaal kapitaal, omdat deze contacten waarschijnlijk als eersten aangesproken zullen worden wanneer het aankomt op het geven van steun en hulp aan mensen met een chronische aandoening of beperking. Er bestaat een hoge mate van consensus over het basisprincipe van (informeel) sociaal kapitaal, namelijk dat het een belangrijke hulpbron kan zijn in het leven voor emotionele en praktische steun. Echter, om sociaal kapitaal te verwerven en te behouden, is het ook belangrijk om in relaties te kunnen investeren. Hiervoor zijn ook hulpbronnen nodig. Een voorbeeld hiervan zijn financiële middelen: wanneer een vriendengroep eens uit wil gaan eten of wanneer men verder weg wonende vrienden wil bezoeken, dan maken voldoende financiële middelen het makkelijker om hieraan mee te doen en deze contacten te behouden. Een goede gezondheid is ook een hulpbron die het gemakkelijker kan maken om informele contacten te kunnen onderhouden (en een minder goede gezondheid dus een belemmering). Deze belemmering kan uit verschillende soorten barrières bestaan, zoals het hebben van te weinig energie om naar mensen toe te gaan of het gevoel dat een bepaalde reciprociteit niet mogelijk is in de relatie.

In dit proefschrift kijken we naar deze mechanismen vanuit verschillende contexten. Dat zijn ten eerste Europese samenlevingen en Nederlandse gemeenten, omdat deze elk op zich verschillende typen beleid kunnen hebben die van invloed kunnen zijn op de relatie tussen het hebben van een chronische aandoening of beperking enerzijds en anderzijds informeel sociaal kapitaal. De vraag is in hoeverre samenlevingen en gemeenten hun inwoners op bepaalde manieren ondersteunen en compenseren met hulpbronnen die nodig zijn om informeel sociaal kapitaal te verkrijgen en te behouden. Ook kijken we naar één specifieke chronische aandoening (coeliakie) en kijken we naar de rol van informeel sociaal kapitaal in zorggebruik van mensen met een chronische aandoening of beperking.

Uitkomsten: de relatie tussen het hebben van een chronische aandoening en informeel sociaal kapitaal in verschillende contexten

In *hoofdstuk 2* trachten we deze vraag te beantwoorden in verschillende Europese landen. Hiervoor maken we gebruik van grootschalige data van de European Social Survey (ESS). Uit deze data blijkt allereerst dat in (bijna) alle landen geldt dat mensen die zich belemmerd voelen door een chronische aandoening of een beperking, over minder informeel sociaal kapitaal beschikken dan hun medeburgers die geen chronische aandoening of beperking hebben. Op individueel niveau blijkt dat dit verschil vooral verklaard wordt door depressieve gevoelens, het slechter beoordelen van de eigen gezondheid (subjectieve gezondheid) en slechter financieel kunnen rondkomen. In dit hoofdstuk kijken we verder naar verschillende typen welvaartsstaten, gebaseerd op de indeling van, onder andere, Esping-Andersen. Deze indeling is gebaseerd op het idee dat samenlevingen verschillen in ‘decommodification’: de mate waarin samenlevingen hun inwoners ondersteunen of compenseren voor een (tijdelijk) gebrek aan hulpbronnen, bijvoorbeeld door sociale zekerheidswetten. Zo zien we dat inwoners in Scandinavische landen het hoogst en voormalig USSR landen het laagst scoren als het aankomt op de hoeveelheid informeel sociaal kapitaal. In sommige gevallen geldt dat de negatieve relatie tussen het hebben van een chronische aandoening en informeel sociaal kapitaal nog sterker is, bijvoorbeeld voor mensen met een chronische aandoening in post-communistische samenlevingen. Ook gaan we in dit hoofdstuk na of verschillen tussen samenlevingen in de uitgaven aan de gezondheidszorg uitmaken voor de mate waarin mensen met en zonder chronische aandoening of beperking verschillen in het bezit van informeel sociaal kapitaal. Het resultaat laat zien dat hoe meer samenlevingen uitgeven aan gezondheidszorg, des te meer informeel sociaal kapitaal de burgers hebben en geldt dat het verschil tussen inwoners met en zonder een chronische aandoening daardoor verkleind wordt (dit geldt alleen door mensen die ‘tot zekere hoogte’ beperkt zeggen te zijn door een chronische aandoening).

In *hoofdstuk 3* werken we hetzelfde idee uit als in hoofdstuk 2, maar dan toegespitst op verschillen tussen Nederlandse gemeenten. Omdat gemeenten in Nederland sinds de invoering van de Wmo de taak hebben gekregen tot het ondersteunen van mensen met een chronische aandoening (zie hiervoor), is het interessant te bekijken of dit ook geleid heeft tot verschillen in de relatie tussen het hebben van een chronische aandoening of beperking en informeel sociaal kapitaal van hun inwoners. De verwachting daarbij is dat gemeenten mogelijk verschillen in de uitvoering van de Wmo en daarmee ook verschillen in de mate waarin ze hun inwoners ondersteunen in het behouden van hun informeel sociaal kapitaal (zie hiervoor). Het idee van Esping-Andersen ‘projecteren’ we daartoe op het politieke stelsel van Nederlandse gemeenten, waarbij we een indeling gemaakt hebben op basis van het niveau van ‘decommodification’ dat verschillende politieke partijen ‘ideologisch’ voor ogen hebben die in de gemeenteraden vertegenwoordigd zijn. Voor de empirisch toetsing in dit hoofdstuk maken we gebruik van twee panels: het Nationaal Panel Chronisch zieken en Gehandicapten en het Consumentenpanel van het Nivel. Verschillen tussen Nederlandse gemeenten in sociaal kapitaal blijken minder groot dan verschillen tussen Europese samenlevingen. Ook de politieke samenstelling van de gemeenteraden lijkt weinig invloed te hebben op de relatie tussen het hebben van een chronische aandoening of beperking en informeel sociaal kapitaal. Alleen voor mensen die ernstig beperkt zijn door een chronische aandoening, geldt dat in gemeenten die een politieke samenstelling hebben die meer focust op ‘decommodification’, het verschil in informeel sociaal kapitaal kleiner is.

In *hoofdstuk 4* zoomen we in op een specifieke chronische aandoening, namelijk coeliakie. Coeliakie is een auto-immuunziekte waardoor (sporen van) gluten (een eiwit in tarwe, gerst en rogge) een ontsteking in de dunne darm veroorzaakt. De enige behandeling is een levenslang strikt glutenvrij dieet volgen. Aan de ene kant is het voor de meeste mensen met coeliakie goed mogelijk om (bijna) klachtenvrij te leven, zolang het dieet goed wordt gevolgd. Aan de andere kant wordt coeliakie als beperkend gezien in sociale zin, omdat eten bij uitstek een sociale bezigheid is. Daarom is dit een interessante groep om onze hoofdrelatie ook in te onderzoeken. Voor dit hoofdstuk is een grootschalige vragenlijst uitgezet onder leden van de Nederlandse Coeliakie Vereniging en gebruik gemaakt van non-random convenience sampling. De respondenten hebben vervolgens iemand in hun omgeving zonder coeliakie gevraagd ook een vragenlijst in te vullen, zodat hiermee een controlegroep zonder coeliakie kon worden gevormd. Uit de multivariate analyses blijkt dat mensen met coeliakie niet veel verschillen van personen zonder coeliakie qua informeel sociaal kapitaal. De initiële verschillen die we vonden, verdwijnen namelijk als we ook kijken naar andere (achtergrond)kenmerken van respondenten. Individuele factoren zoals gevoelens van depressie verklaren een deel van de verschillen, maar het grootste deel van de verschillen hangt samen met (demografische) achtergrondkenmerken. Mogelijk is het feit dat veel mensen met coeliakie weinig tot geen klachten ervaren, vooral dankzij het volgen van een glutenvrij dieet, hiervoor een verklaring. Mogelijk voelen zij hierdoor minder beperkingen van deze chronische aandoening. We zagen immers in de twee voorgaande studies, dat de mate waarin mensen zich beperkt voelen door een chronische aandoening uitmaakt voor de relatie tussen het hebben van deze aandoening of aandoening en het bezit van informeel sociaal kapitaal. Een andere verklaring kan liggen in de manier van data verzamelen voor deze studie: hoewel we hebben gevraagd de vragenlijst voor de controlegroep naar bijvoorbeeld kennissen te sturen, kozen de meeste respondenten ervoor de vragenlijst naar de partner of naar familie te sturen.

Eén van de ideeën achter de invoering van de Wmo en andere beleidswijzigingen voor het Nederlandse zorgsysteem van de afgelopen jaren, is dat mensen eerst op hun eigen netwerk en zelfredzaamheid moeten terugvallen zodat het gezondheidssysteem houdbaar blijft. In deze context onderzoeken we in *hoofdstuk 5* in hoeverre het zorggebruik verschilt tussen mensen met een chronische aandoening (en verschillende maten van beperkingen) en welke rol informeel sociaal kapitaal hierin speelt. Voor de analyses gebruiken we opnieuw data vanuit het Nationaal Panel Chronisch zieken en Gehandicapten van het Nivel. Uit de resultaten blijkt dat het bezit van informeel sociaal kapitaal van mensen met een chronische aandoening of beperking samenhangt met een kleinere kans om psychologische zorg en zorg vanuit de Wmo te gebruiken, maar voor andere typen zorg (huisartsenzorg, medisch specialistische zorg en zorg van paramedici) geldt dit niet. We onderzochten ook of de relatie tussen het hebben van een chronische aandoening of beperking verschillend is voor mensen met meer en minder informeel sociaal kapitaal. Hier vonden we geen verschillen.

Conclusie en beschouwing

In een interview met de Volkskrant (gepubliceerd 8 mei 2022) zei voormalig directeur van het SCP Kim Putters: “Er is een sterke neiging te denken vanuit maatregelen waarnaar mensen zich moeten gaan gedragen, in plaats van te denken vanuit mensen. [...] Je moet de mensbeelden toetsen: kloppen je aannamen?”. In lijn met dit citaat hebben we met dit proefschrift een aantal van de aannamen rond het beleid voor mensen met een chronische aandoening of beperking onderzocht. We zien dat voor mensen met een chronische aandoening of beperking het hebben van meer informeel sociaal kapitaal samenhangt met een kleinere kans op het gebruik van psychologische zorg en zorg vanuit de Wmo. Tegelijkertijd is het niet vanzelfsprekend dat mensen met een chronische aandoening of beperking voldoende informeel sociaal kapitaal hebben om op terug te vallen. Daarmee is de verwachte zelfredzaamheid ook voor lang niet iedereen een gegeven. Dit voedt het idee dat een bepaalde mate van ondersteuning en stimulans van (informeel) sociaal kapitaal nuttig kan zijn. Aansluitend daarbij vinden we in dit onderzoek dat bepaalde contextfactoren mensen lijken te kunnen helpen bij het behoud van hun informeel sociaal kapitaal. De mate waarin mensen informeel sociaal kapitaal bezitten hangt samen met de mate waarin samenlevingen hun inwoners ondersteunen of compenseren voor een (tijdelijk) gebrek aan hulpbronnen (‘decommodification’) en de hoeveelheid geld die wordt uitgegeven aan de gezondheidszorg. Voor sommige groepen met een chronische aandoening of beperking is dit nog belangrijker en lijkt dit hen te helpen om hun informeel sociaal kapitaal te behouden. Veel vervolgvragen kunnen gesteld worden over de invloed van andere contextfactoren. Dit zou gemeenten verder kunnen helpen in het ondersteunen van hun inwoners in het behouden van informeel sociaal kapitaal en het stimuleren van de inzet hiervan.

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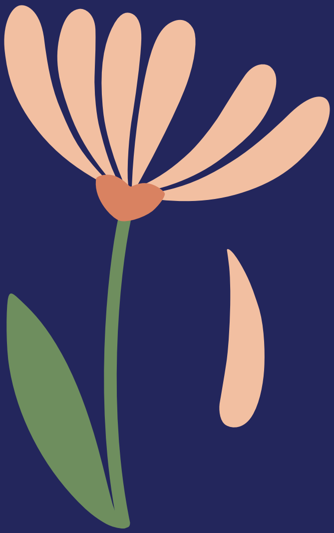
Dankwoord



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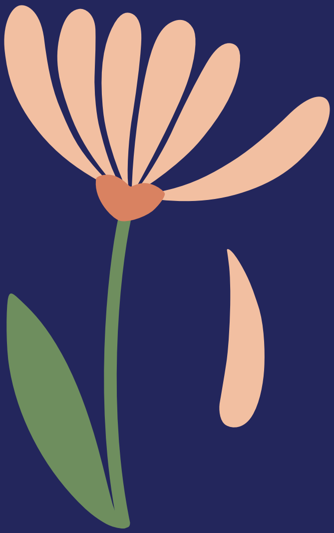
ABOUT THE AUTHOR



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Elize Vis was born in Vlaardingen, the Netherlands, on the 25th of August, 1991. She obtained her Bachelor’s degree in Sociology in 2014 and her Master’s degree in Social and Cultural Science in 2016 at the Radboud University in Nijmegen. After obtaining her Master’s degree, she started working at Nivel (Netherlands Institute for Health Services Research) and is currently still employed here. In 2018 she started as an external PhD candidate under the supervision of Prof. Dr. Peer Scheepers and Prof. Dr. Ronald Batenburg at the Department of Sociology at the Radboud University. At Nivel, Elize works on national and international research projects concerning manpower planning in healthcare, healthcare systems, (regional) labor market problems and education of healthcare professionals.

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