

# **Social Capital in Online Migraine Communities**

Jacqueline van der Marel (312330)

312330jm@student.eur.nl

Anna van Burenstraat 78

3136 CH Vlaardingen

Supervisor: Dr. S. Adams

Co-evaluator: Drs. M. Aspria

Co-evaluator: Dr. K. Grit

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## **Preface**

This thesis 'Social capital in online migraine communities' has been written with the purpose of completing my Masters degree in Health Economics, Policy and Law at the Department of Health Policy and Management (iBMG) of the Erasmus University Rotterdam. Starting point was an interest in social capital theory and the observation that social networking sites are becoming increasingly important in social life. This was coupled with my own experience as a migraine patient and the experiences of family members and friends suffering from migraine.

This thesis could not have been accomplished without the enthusiastic supervision of Dr. Samantha Adams. I would therefore like to take the opportunity to thank her for the advice, comments and suggestions on earlier drafts. Also thanks to co-supervisors Drs. Marcello Aspria and Dr. Kor Grit for their contribution to the process and their comments and suggestions on the thesis proposal. Furthermore, migraine.com must be thanked for their cooperation and for placing my research call on their website. Finally I would like to thank the participants of migraine.com and migraine sufferers for sharing their personal migraine story and experiences with other patients. Special thanks go out to the respondents that participated in my research. Without their stories and willingness to participate this thesis could not have been completed. To pay tribute to their comments I would like to express the hope here that the readers of this thesis will gain more understanding of migraine and approach patients with more compassion.

## Summary

Over the last decades the Internet has dramatically changed the information and network infrastructure and created opportunities for participation and empowerment. This is especially emphasised in the health-care sector. Social media like Facebook (FB) are becoming an integrated part of social life and are likely to become a more important tool for people with chronic diseases in the future. This thesis will therefore address what online communities mean for patients with a chronic disease such as migraine and how they experience the ascribed benefits of online communities.

The aim is to gain insight in how migraine communities on FB facilitate interaction. The research question of this thesis is: 'How do community ties on online communities provide patients with access to resources that are related to their health?' To answer this question a qualitative research design was chosen that combined document analysis, observations and semi-structured e-interviews. A total of sixteen respondents from migraine.com and six respondents from migraine sufferers were interviewed. The data were thematically analysed based on the themes: motives and goals, investment, (meaning of) resources and community ties.

The research showed that participants of online communities can have two goals for participation. Firstly they are hoping to find more, other and new information. Secondly, participants are looking for social interaction and support. Some participants spend a substantial amount of their time on the online community but even small gestures were enough to establish interaction. Three types of resources were recognised by participants: information resources, interaction resources and support resources. Information resources included up-to-date, medical and experiential information. Interaction resources include getting advice and feedback. Support resources are based on understanding, empowerment and validation. Shared experiences played an integral part in this, because no one but another patient could grasp the experience of having a migraine. These resources could be accessed depending on the type of tie between participants. No ties indicate no sense of recognition between participants and superficial ties refer to acquaintances, while close ties refer to friendships.

It can be concluded that the community ties are essential in gaining access to particular resources. Interaction is necessary to establish community ties and is therefore the driving force behind the production and continuation of social capital. Social capital is a mechanism to access resources and requires individual and collective action.

Finally the website of migraine.com that was attached to the FB community illustrated that bringing together information, interaction and support gives patients the opportunity to take up the role of active and informed patient that they are often assigned to.

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## 1. Introduction

Over the last decade the Internet has been one of the fastest growing technologies in the world and the amount of Internet users has been rising explosively. The increased access to the Internet is reflected in the amount of Internet users per 100 people. In the United States of America (USA) this percentage has increased from 0,8% in 1990 to 43,1% in 2000 and 74,2% in 2010. Worldwide this percentage rose from 0,0% in 1990 to 6,7 % in 2000 and 30,2% in 2010 (Worldbank 2012). The big difference between the USA and other parts of the world reflects the uneven spread of the Internet also referred to as the 'digital divide' (e.g. Compaine 2001; Norris 2001; Selwyn 2004). Nonetheless, the Internet has dramatically changed the way in which information can be searched and shared (Parent & Cruickshank 2009:91). Moreover, individuals are able to exchange information and create networks that transcend time and space (Lin 1999:46).

The changing information and network infrastructure has created opportunities for participation and empowerment which is especially emphasised in the health care sector, where the patient is often re-conceptualised as a: reflective, informed or expert patient, healthcare consumer, active participant, and manager of his or her own health (Eysenbach 2000; Ferguson 1997; Gray 2002). The Internet potentially enables easier access to information regarding illness because formal institutions - such as professionals or governmental institutions - are no longer needed to access information. Moreover the line between information users and producers as well as the line between expert and lay knowledge becomes blurred as patients increasingly produce information for another (Malina 1999:24; Seale 2003:516). Research reflects this development and indicates that individuals use the Internet to seek health-related information more than ever (Eaton 2002).

Besides the informational function of the web, social media applications have specifically accelerated the opportunity for empowerment and participation. Channels like Facebook (FB), Twitter and YouTube are constantly growing and have an increasing amount of health-related applications. Examples are blogs of patients documenting their illness, health-related communities on FB, rating sites such as 'Rate my doctor' and applications ('apps') for mobile phones such as the 'Healthy Heart Journal' where patients can monitor blood pressure, pulse and medication (Adams 2010; Apple 2011; Facebook 2012a; Hackworth & Kunz 2011; Hawn 2009:364). Although exciting in theory, the question is whether the endless opportunities of social media and the ideal of an active patient will be achievable in practice as the opportunity for empowerment and participation does not equal the realisation of such goals (e.g. Adams & de Bont 2007; Adams 2011; Barbot 2006; Lemire 2010; Mort et al. 2009). Patients' inability to appraise information found online and the negative responses from medical professionals regarding information assimilation by patients can be seen as barriers towards the ideal of an empowered patient (Henwood et al. 2003;

Jacobson 2007; Kivits 2006). This thesis therefore addresses what social network sites mean for individual patients and how and if they experience the ascribed benefits.

This research has specifically focussed on FB communities as an example of social media. This is because FB is becoming a part of life for many people since FB has more than 800 million active users of which 50% log on daily (Facebook 2012b). Also, traditional Internet forums and support groups are increasingly relocating to FB because of its high activity, large amount of users worldwide and its user friendliness (Ross et al. 2009). FB will therefore likely become a more important tool in the future, especially for people with chronic and/or hard to diagnose diseases.

This thesis focuses on one such condition, migraine. This disease is difficult to diagnose and requires an individual treatment. Moreover, many patients do not respond satisfactory to regular therapies and are in a life long journey to find relief (Winter et al. 2011:148). Online communities may provide patients with an infrastructure that enables them to assess the right therapy and it may also provide a platform for social support, as most migraine patients feel their symptoms are trivialised and misunderstood (WHO 2004).

To gain insight in the benefits of online migraine communities, this thesis focuses on the goals and motivations for participation as well as the meaning of the community ties for individual patients. A theory that allows to go beyond the social networks and the relationships itself and focus on the resources for patients that are embedded and accessed through those relations is social capital theory (Lin 1999:37). This theory is based on the notion that investments in social relations provide individuals with resources otherwise unavailable to them. Although some research has been conducted regarding the application of social capital to online communities, uniform scientific groundwork is lacking (Nie et al. 2002:216). This thesis will therefore help to further develop social capital theory into the online world. The purpose of this thesis is to gain insight in how migraine communities on FB facilitate interaction and provide patients with certain resources that would otherwise be unavailable to them. The research question of this thesis is:

*How do community ties on online communities provide patients with access to resources that are related to their health?*

In order to answer this research question, the following sub-questions will be discussed:

1. Why do patients participate on online communities?
2. What do patients invest to be a participant on online communities?
3. What kind of resources do patients that participate on online communities recognise?
4. What do these resources on online communities mean for patients?
5. What are the characteristics of community ties on online communities?

The next chapter will begin with an analysis of issues in migraine diagnosis and treatment and will briefly address the two empirical cases. This chapter will be followed by a theoretical chapter about social capital theory. The origin and key authors of (social) capital theory will be outlined and social capital research in online communities will be discussed. In addition some key concepts will be explicated. Chapter five will discuss and motivate the research methods and emphasise the strengths and weaknesses of these methods. In chapter six key results from the observations and interviews will be displayed. These results will be discussed and placed within the social capital framework in chapter seven. This chapter also includes answers to the sub-questions and a reflection on this thesis. Finally, the research questions will be answered and recommendations for further research will be provided in the conclusion.



## **2. Problem analysis**

This chapter discusses the symptoms of migraine and the consequences for patients and society. Furthermore issues in current migraine diagnosis and treatment will be highlighted. The two online migraine communities that are used as an empirical case in this thesis will also be discussed.

### **2.1 Migraine**

Migraine is a chronic cardiovascular disorder that is characterised by regular episodes of extreme headache (Goadsby et al. 2002:257). The most common symptoms include: episodes of headache varying from a few hours to several days, pounding and intense headache that worsens, hypersensitivity to sound and light, nausea and vomiting. In approximately 30% to 35% of migraine cases these symptoms are preceded by an aura. Auras cause visionary problems such as flashes, partial loss of vision and coloured flares. Other neurologic symptoms are the inability to speak or understand conversation, tingling in parts of the body and weakness in one side of the body (Goadsby et al. 2002:257; LUMC 2012). These symptoms distinguish migraine from other headaches such as tension-type headache that lack a combination of these symptoms (Goadsby et al. 2002:257).

Migraine is a condition that affects a large proportion of the population. In Europe 18,5% of the population is affected by migraine and this percentage is even higher in women (Leonardi et al. 2010:23). Research indicates that at least 10% of migraine patients have weekly attacks that on average last 24 hours and 20% of migraine patients have attacks that last two to three days (Goadsby et al. 2002:257). These attacks cause severe suffering and restrict patients substantially (Leonardi et al. 2005:430; WHO 2004). This suffering and disability is reflected in a survey by the World Health Organisation (WHO) that rated severe migraine as one of the most disabling chronic conditions alongside psychosis, dementia and quadriplegia (Menken et al. 2000). Worldwide, migraine ranks 19<sup>th</sup> as a cause of years lived with disability (WHO 2004).

Although the WHO has recognised the severity of migraines, this chronic condition is often trivialised and not taken seriously by employers, colleagues, friends and family members. There is a general lack of understanding of the degree of suffering from migraines. Stovner & Queiroz (2011:38) argue that this trivialisation of headaches as a public health problem has far-reaching implications such as “inadequate resources to headache treatment and prevention, little attention in the curricula in medical schools, low funding of headache research and lack of understanding for headache among relatives, employers, teachers and colleagues”. Especially the lack of understanding and social support is emphasised by patients, indicating that migraine has a substantial effect on their social functioning (WHO

2004). Attacks can limit or prevent patients from attending social gatherings and engage in relationships. Some patients are even unable to leave their house because of having a migraine or the fear of triggering one (Stronks 2003:20). Some researchers suggest that migraine can have a deleterious effect on social relationships (Dowson & Jagger 1999; Kryst & Scherl 1994).

Besides the individual consequences of migraine, there are also societal consequences resulting from the proportion of the population that is affected by migraines. Research indicates that migraine patients experience a significant reduction in their quality of life in the domain of work functioning (Lipton et al. 2001:643-644; Santanello et al. 1995). When faced with migraines, they become more concerned with their medication and their migraine and this reduces work functioning. Because migraine prevalence peaks in the 'productive' years – 20 to 65 years – there is a loss of productivity due to reduced work efficiency and absenteeism (Leonardi et al. 2010:23). The costs of migraine in Europe are estimated to be 27 billion Euros (Andlin-Sobocki et al. 2005; Berg & Stovner 2005). This indicates that society as a whole can benefit from reducing the migraine burden.

## **2.2 Migraine treatment**

A major problem in current migraine practice is underdiagnosis. Although the amount of patients receiving a medical diagnosis has increased, there is still a large proportion of patients that remains undiagnosed. According to Gallagher (2004:9) this concerns 50% of patients, which is mainly due to the lack of medical consultation for headaches in general. Although consultation in western countries like the USA has increased, the majority of migraine patients does not consult a doctor for their headaches (Lipton et al. 2001:642-643). When patients do consult a doctor adequate diagnosis is complicated because of the retrospective nature of migraine symptoms and time restraints. Patients usually visit their doctor after experiencing a migraine attack. This leaves the doctor to rely on patient's retrospective description of symptoms (Lipton et al. 2001:643). Also the short consultation time per visit does not enable patients to provide doctors with the essential information for appropriate diagnosis and treatment (Carr-Hill et al. 1998).

When patients are diagnosed with migraine, different treatment options are available. Non-pharmacologic treatment is aimed at educating the patient about their illness. Lifestyle changes for instance, can help reduce the triggers of a migraine attack. Advice includes: regular sleep and meals, exercise and the avoidance of stress and dietary related triggers such as chocolate and caffeine. The aim is to establish a stable and regular lifestyle in order to avoid peaks that affect the brain. A frustration for many patients is the fact that every

patient has different triggers and that all patients have a different sensitivity to these triggers (Goadsby 2002:260).

Pharmacologic treatments can be divided into medication that is taken daily and medication that is taken at the beginning of a migraine attack. Daily medication is used as a preventative to reduce the amount and severity of migraine attacks and is therefore sometimes referred to as preventive treatment. Attack medication on the other hand includes non-specific medication such as aspirins and opiates that are used for pain relief. It also includes specific medication such as triptans that are used for the treatment of neurovascular disorders. This treatment is sometimes referred to as symptomatic treatment since it is aimed at reducing or aborting migraine attacks and its symptoms (Goadsby 2002:260; Saper 1997:1).

The effectiveness of these treatments will depend on specific patient characteristics such as the amount, severity and nature of migraine attacks (Goadsby 2002:260; Saper 1997:1). Many patients will not respond satisfactory to particular treatments thus an individual approach is needed to assess whether preventive or symptomatic treatment will be beneficial (Saper 1997:1; Winter et al. 2011:148). However, poor patient-doctor communication can be a barrier to this individual approach and for receiving appropriate care (Blau & MacGregor 1995; Lipton et al. 2000). This leaves many patients with unmet treatment needs and continuous pain and suffering (Silberstein 2000).

### **2.3 Migraine case studies**

Two online migraine-related Facebook communities were examined in this research. This social networking site currently has more than 800 million active users worldwide of which 75% outside of the USA. Half of those users log on daily to keep in touch with friends, upload photos, videos and comments and learn more about friends and other people (Facebook 2012b; Facebook 2012c). With the integration of FB in daily life health-related communities have been emerging.

#### ***Migraine.com***

'Migraine.com' is one of those health-related communities on FB. This community is linked to the website of migraine.com and includes comments from patients but also links to articles on the website. The outline of the FB community is displayed in Appendix 1. The website itself provides information, tools, expert discussion, and forums and is displayed in Appendix 2. The mission of migraine.com is to "empower patients and caregivers to take control of migraine disease by providing a platform to learn, educate and connect with peers and healthcare professionals" (Facebook 2012d). Migraine.com is dedicated to provide accurate

information that comes from trustworthy sources such as peer-reviewed journals and the International Headache Society. Articles placed on the website are also reviewed by a board of physicians and neurologists (Facebook 2012d).

### ***Migraine sufferers***

'Migraine sufferers' is the second case and was selected because of the daily activity and the amount of patient's comments. (For further discussion see methods section.) This FB community has 2649 members and can be viewed by all FB users. The group attracts members by stating that: "if you are a sufferer of migraines and would like to meet other people who have the same problem and you would like to share and get advice about how to cope with them, this is the group for you to join" (Facebook 2012e). The outline of the community corresponds with the uniform FB format and is displayed in Appendix 3.

Social capital theory will be used to analyse the two cases described above. This theory was chosen because the aim of this research is to assess what online communities mean for individual patients and whether they experience the ascribed benefits. Especially migraine patients are theoretically able to benefit from online communities since sufferers from this chronic condition may find social support and find information that helps them put together an individually suited therapy. To assess whether migraine patients on migraine.com and migraine sufferers experience the ascribed benefits, social capital theory will be applied. Social capital theory allows to go beyond the social networks and the relationships itself and focus on the resources for migraine patients that are embedded and accessed through those relationships (Lin 1999:37). This theory and the perspective that will be used to understand and analyse the two cases will be explicated in the next chapter.

### **3. Social capital theory**

In the last twenty years the concept of social capital has captured the interest of a wide range of scholars from different academic disciplines such as economics, education and public health. These scholars have contributed to the literature on social capital from their own disciplinary perspective, resulting in multiple definitions, conceptualisations and measurement formats of social capital (Ferlander 2007:115; Lin 2008:52; Poder 2010:3; Portes 1998:3; Woolcock 1998:193-196). The concept and its different contributions have therefore been critiqued on vagueness surrounding meaning, measurement and outcome (Hawe & Shiell 2000; Lynch et al. 2000; Muntaner et al. 2000; Schuller et al. 2000). However, there is consistency across the work of various scholars. To outline this consistency and gain understanding on the theory of social capital, the next paragraph will focus on the origin of the concept of capital. Secondly, different perspectives within social capital literature will be discussed. It must be emphasised that the following discussion is by no means inclusive nor is it intended to be considering the scope of social capital literature. The goal is rather to give the reader some understanding of social capital literature and the key authors within this academic field. Finally social capital in relation to online communities will be discussed.

#### **3.1 Capital theory**

When discussing the origin of capital theory, Karl Marx is (one of) the key authors to consider. The concept of capital dates back to Marx's (1849) analysis of class exploitation and social relations between the capitalists and labourers in the emergence of capital. Marx's (1849) analysis is based on the fundamental argument of class differentiation between the capitalist society (or the bourgeoisie) and the labourers. In his analysis Marx argues that capitalist society exploited labourers in the production process because profit is an emergent property of production which is produced by the labourers but owned by the capitalists (Fuchs 2010a:183). According to Marx (1867) the capitalists take advantage of the lower input costs than the output prices of commodities. This difference – called 'surplus value' – was appropriated by the capitalists, but produced by the labourers (Marx 1867). Part of this surplus value is reinvested in the production process so that new surplus value can be created. This means that: "capital is money that is permanently increasing due to the exploitation of surplus value" (Fuchs 2010a:183). Capital was both part of the surplus value generated by the capitalists as well as an investment of the capitalists with expected returns or profit (Lin 2001:4-7). Capital can therefore be conceptualised as the investment of resources for the production of profit (Lin 2001:8).

Through his extensive contributions Marx inspired many scholars to focus their academic work on capital theory. However, Marx's classical theory has gradually evolved in what have been dubbed 'neo-capital theories' that have adapted and adjusted Marx's

arguments. A main difference is that class differentiation is no longer a fundamental argument in many neo-capital theories. Although some authors do explicitly focus on class, such as work by Fuchs (2010a; 2010b; 2011) and Ritzer & Jurgeson (2010). Their work is concerned with capitalism and class exploitation related to the Internet and social media such as FB, YouTube and MySpace.

Fuchs (2010b:142) argues that we live in a society of informational capitalism where knowledge has become a productive force. Informational content is produced by enterprises but also in everyday life, for instance by users of social network sites. The Internet and social media applications allow their users to produce content collectively so that the line between information production and consumption becomes blurred (Ritzer & Jurgeson 2010:19). According to Fuchs this 'prosumption'<sup>1</sup> allows the users of social network sites to become producers of knowledge that provide free labour for the owners of those sites (Fuchs 201a:147). This labour can generate a profit for the owners of social network sites for example through advertisement rates (Fuchs 2010a:147,191-192; Fuchs 2011; Ritzer & Jurgeson 2010:29). The richness of data available on social network sites allows commercial companies to create personalised marketing strategies. According to Manzerolle (2010:462) the social media applications "reflect a new web-based marketing approach that strategically employs user-generated content in the production and targeting of commercial messages". This means that the users of social network sites become a commodity that is sold to advertisers (Fuchs 2010a:147,191-192; Fuchs 2011).

Although the users of social network sites have become more involved in the production of those sites - through the generation of content and access to production properties such as the ability to customise their own page - the (potential) profit is retained by the owners of the sites (Ritzer & Jurgeson 2010:26-27). The users of social network sites therefore produce information that is appropriated by capital (Fuchs 2010b:142). Because capital is produced by a different class than the class that appropriates the surplus value of capital, the users of social network sites arguably become an exploited class just like the labourers in Marx's analysis (Fuchs 2010b:142).

Another feature of neo-capital theories is the level of explanation that has shifted from macro and meso level to micro level. Where capital was seen as part of the process of class exploitation (macro) in the past, it now focuses on individual actors (micro) and their investment of personal resources to gain surplus value (Lin 2001:17). In these neo-capital theories different types of capital are distinguished such as human, cultural and social capital. However social capital is unique because the purely individual perspective (that underlies human and cultural capital) is expanded where capital is seen as a social asset.

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<sup>1</sup> For discussion see Toffler 1980

This means that capital can be captured through social relations and that surplus value is generated through investment in social relations (Lin 2001:19). An example may be that individuals that participate in an online community and thereby invest in their social relations can gain access to valuable information that would otherwise be unavailable to them. This information can be seen as the surplus value.

This concept of social capital underlies the work of many authors. As Lin (2001:19) argues: “[social capital is seen as a] investment in social relations with expected returns” (Lin 2001:19). This consistency clearly descends from Marx’s notion of capital and will be discussed in the next paragraph.

**3.2 Perspectives on social capital**

A frequently used distinction in social capital literature is based on the different levels at which the return of social capital is conceived (Lin 2001:21). The levels of analysis range from individuals, social groups, formal organisations, ethnic groups and nations (Bankston & Zhou 2002; Brewer 2003; Coleman 1988, Putnam 1995; Sampson et al. 1999). Generally three levels are distinguished (see figure 1). Narayan & Pritchett (1999:872-873) for example divide social capital research into three streams: country-level politics (macro), efficacy of organisations (meso) and solutions to market failure (micro). Lin et al. (2001:7-8) make a distinction between social capital at the individual level and at group level. At group level research focuses on the exploration of the production and continuation of the collective asset of social capital. At the individual level research is directed at the way individuals invest in social relations and how they capture the embedded resources within those relations. Halpern (2005:16-19) also defines three categories of social capital: state and nation connections (macro), organisations (meso) and close ties such as family and friends (micro).

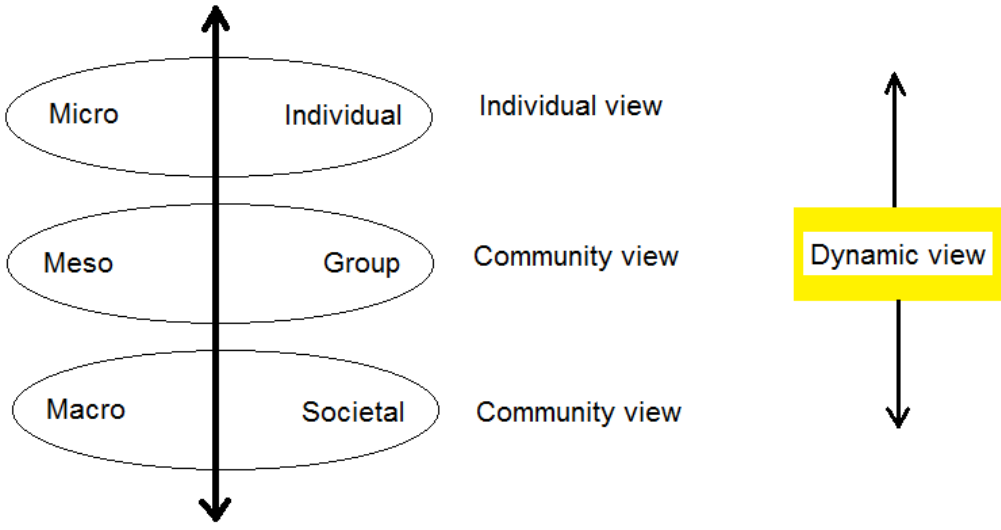


Figure 1. Levels at which social capital can be perceived and the views that are attached to this (Alternated version from the original image of Clardige 2012)

Besides these three levels, two views of social capital theory can be distinguished. These two views show some overlap with the three levels mentioned earlier (see figure 1). The community view overlaps with the meso and macro level and perceives the level of return at group or community level. Social capital is conceived as a social feature that is reflected in the structure of social relationships (Baum & Ziersch 2003:320). Most work revolves around comparisons of groups with more or less social capital than the other (e.g. Carlson 2004; Sampson et al. 1999). Focal point in this research is how a difference in social capital affects the lives of different groups in society (Lin 2001:22). James Coleman is an author that can be placed within this research tradition with his work on the relationship between social inequality and academic achievements (Schuller et al. 2000:5-6). His work reflects a group level perspective because collective capital is maintained by close community relationships which enable group reproduction (Lin 2001:23).

Coleman has been an influential author in social capital literature since he was one of the first who explicitly linked social capital and access to resources. Moreover, post-Coleman literature has almost universally adopted a community perspective. This means that most social capital frameworks are based on aggregate definitions of social capital as a community attribute (Glaeser et al. 2002). Putnam has adapted this community view and even cites Coleman in his iconic work on regional governments in Italy (Putnam 1993). Nevertheless, Putnam has overshadowed Coleman in current theoretical debates. Putnam contributed by popularising the term and introducing it in political discourse through his essay *Bowling Alone* (1993) in which he argues that social capital in America is declining by an example of national bowling leagues (Schuller et al. 2000:9). According to Putnam the decline of social capital in America can be attributed to the increased amount of time spend watching television that partly substitutes the time spend in social organisations such as bowling leagues (Putnam 1996).

Although Putnam is one the most cited authors in social capital literature, his work has also been subject to critique. Norris (1996:479) for instance has critiqued Putnam's argument that television has contributed to the decline of social capital through the lack of confidence and trust in American democracy. According to her this argument is "unproven" and "deeply implausible" because of the complex relation between television and civic engagement (Norris 1996:479). Although the time spent watching television has increased and supports Putnam's argument, Putnam has not incorporated the content of what is viewed in his research. Watching news and actuality programmes may not be damaging for society and may even be beneficial. It is therefore problematic that Putnam argues that social capital is declining due to television in general.

Another critique has been that Putnam does not address issues of power and conflict. Putnam links social capital to participation in voluntary organisations such as bowling



leagues. He neglects power issues because he finds social capital observed in voluntary organisations incompatible with high levels of inequality (Schuller et al 2000:10). However, even voluntary organisations can carry unequal power relations, because this is inherent in all modern associations. Weber (1911) argued that these unequal power relations in modern associations can be observed internally and externally. Internally there is a hierarchical difference between the leadership of the organisation and the regular employees. Externally there is a divide between members of the organisation and the rest of the world (Siisiäinen 2000; Weber 1911). This indicates that unequal power relationships and issues of conflict can always be observed, but that Putnam does not address these issues. According to Davies (2001) Putnam can therefore be placed within a neo-Liberalist model of social capital which is critiqued on the same point of power issues. This perspective is countered by a neo-Marxist theoretical model that is better able to address issues of power and conflict. The neo-Marxist model is characterised by more emphasis on access to resources.

Finally Portes (1998) critiques Putnam and the community perspective in general. Portes (1998:19-20) addresses the fundamental problem of circularity in Putnam's work, by arguing that social capital "as a property of communities and nations rather than individuals, is simultaneously a cause and an effect". The circularity comes from observing positive effects from social capital and at the same time attributing this to social capital as a cause. As a collective property social capital is often measured in 'stocks' that lead to better governance and policies. The existence of this governance or policy is subsequently inferred from the same outcomes. This inability to disentangle the causes and effects of social capital leads to circular reasoning and is seen as a flaw in most research conducted from a community view (Portes 2000:4). Portes (1998:21) argues that he is not fundamentally against social capital as an aggregate but that current research requires more theoretical refinement. He then goes on to argue that there is more potential and benefit in conceptualising social capital at an individual level, illustrated by an analysis of Bourdieu's work. This is because Bourdieu – according to Portes (2000:4) – "prevented" the individual view of social capital to engage in such circularity. At an individual level, social capital resources are associated with an individual's network while the effects are associated with a collection of material and informational benefits. These effects are separate from the social structure that produced these effects.

Bourdieu (1977) further discussed the interconnectedness of different forms of capital and their role in the reproduction of unequal power relations (Baum 2000:410). According to Bourdieu social capital is a resource that is socially reproduced through the possession of knowledge and the accomplishments of relations and networks. This enables individuals to draw on this resource resulting in individual gain such as privileges, social rewards and status (Bourdieu 1973). Social capital is thus conceptualised as a mechanism to gain access

to resources (Baum & Palmer 2002). This is reflected in Bourdieu's definition of social capital: "the aggregate of the actual or potential resources which are linked to possession of a durable network of (...) relationships of mutual acquaintance and recognition (...) which provides each of its members with the backing of collectively owned capital" (Bourdieu 1997:51).

At the individual level social capital is thus conceptualised as the resources that are available to individuals as a result of their membership of a network (Baum & Ziersch 2003:320). Focus lies on how individuals access and utilise resources embedded in their social networks. Lin (2001:25) for instance defines social capital as: "resources embedded in social networks, accessed and used by actors for actions". The individual approach allows the analysis of individual consequences of social capital, rather than basing conclusions on proxy indicators such as Putnam's associational membership (Portes 2008:19-20). This also allows the assessment of all possible effects of social capital: both negative and positive. Communitarians like Putnam often see social capital as an inherently good attribute that always has a positive effect on communities. This means that more social capital is always better. This notion of social capital however, overlooks 'perverse social capital' like isolated communities or networks that do not act in society's interest (Woolcock & Narayan 2000:229). The individual focus enables to look at the individual effects of social capital and highlights the potential for both positive and negative outcomes. Community ties may create benefits for certain individuals but may also come at the expense of others by restricting or controlling their behaviour (Agneessens 2006). Examples are gangs, drug cartels or the mafia (Woolcock & Narayan 2000:229).

Although both perspectives differ with respect to the level of return, they show some similarities. Both perspectives for instance emphasise the importance of interacting members in a community because the interaction of individuals is the driving force behind the production and continuation of the asset that is social capital. Without interacting members of a community, community ties cannot be constructed. The resources that are embedded within these community ties can therefore not be accessed and social capital at a group level cannot be observed. This means that social capital may have an individual and an aggregate component because it is an asset that belongs to the group but can be used by individuals (Buys & Bow 2002; Sander 2002).

The dynamic view can be seen as an attempt to bring together the benefits of the communitarian and individualistic approaches. This perspective allows the analysis of relationships between micro level social interaction and their role in communities (meso) or society as a whole (macro). Individual interactions (micro) are coupled with critical social theoretical perspectives on meso and macro level, thereby combining different levels of analysis and enabling connections between the empirical data and a broader social meaning

(Falk & Kilpatrick 2000:89). Halpern (2005) also emphasises the relationship between the different levels at which social capital can be observed. He argues that a decline of social capital at one level may be compensated by increases at another level. An example could be weaker ties with family members – indicating declining social capital at micro level – that is compensated by an increase in organisational participation (meso) and nationalism (macro).

It can be concluded that the dynamic view of social capital has the ability to provide a framework that allows analysis of individual social capital while not overlooking the broader social implications of social capital at the community level.

### **3.3 Social capital in online communities**

Although studies of social capital have been subject to critique, many authors emphasise that the wide disagreement and critique does not mean that the concept of social capital is redundant (Lin 1999:48; Schuller et al. 2000:23; Woolcock & Narayan 2000:243). Schuller et al. (2000:23) even argue that it is precisely this disagreement that makes that social capital can provide fresh perspectives and highlight new issues. Lin (2008:53) for example discusses four scenarios in which the added value of social capital can be achieved.

The first is through the facilitation of information channels via the social relations that may provide individuals with useful information that would otherwise be unavailable (Lin 2008:20). In the case of online migraine communities this is plausible as patients can retrieve information on treatment from other migraine patients. Secondly, the social relations may exert influence on different individuals or organisations. An example may be the lobbying of patients for votes on law proposals related to their illness. Third, the social relations may represent an individual's social credentials. This is particularly evident on FB, where the amount of friends as well as the status of friends can be an indication for one's social credentials. Finally, social relations may reinforce an individual's identity. This because the recognition as a worthy member of a social group with shared interests and resources can provide emotional support (Lin 2001:20). It is likely that patients on an online community gain support from their fellow patients (Idriss et al. 2009; Wangberg et al. 2008).

Besides this general theory on social capital that was linked to online communities, Lin (2001:210-239) explicitly explores the relationship between social capital and the Internet. He argues that social capital has been increasing over the last decade due to online social networks (2001:211). This is because online social networks carry resources such as a unique information infrastructure. Moreover, they provide possibilities for exchange and the formation of groups as individuals are able to connect with little time or space constraints (Lin 2001:215). This means that exchanges between a large group of individuals can occur according to the pace in which individuals wish to participate (Lin 2001:227).

Although Lin (2001) convincingly argues that online social networks represent a form of social capital, uniform scientific groundwork is lacking. Research on the impact of the Internet on social capital provides conflicting results, especially regarding the displacement of offline with online interaction (Nie et al. 2002:216). Some argue that more time spent on the Internet will result in less face-to-face interaction (e.g. Kraut et al. 1998). Others argue that there is no displacement of offline with online interaction (e.g. Quan-Haase & Wellman 2004; Woessmann 2011). While other research suggests that online interaction is associated with a higher degree of offline interaction (e.g. Ellison et al. 2007; Miyata 2002). Regarding this debate DiMaggio et al. (2001:316) argue that: “to some extent, whether one views the Internet as corrosive to or supportive of community depends in part on how one evaluates the things people do with it”. Therefore it is important to distinguish between different types of Internet use (DiMaggio et al. 2001:317). In this thesis Internet use will mainly consist of communicative and information-related activities on online migraine communities.

Additionally, the debate surrounding the effect of Internet use on social capital highlights the need to identify the conditions of specific cases in which social capital might increase or decrease (Drentea & Moren-Cross 2005:939). This means that the contextual features of the two migraine communities studied in this thesis may contribute to the increase or decrease of social capital. This may also imply that one migraine community may experience a different degree of social capital than the other since the communities have different features.

## **4. Key concepts**

In the previous chapter some theoretical concept such as (online) community, community ties and resources were mentioned. These concepts may carry conflicting associations. This chapter will therefore be devoted to the exploration and clarification of those key concepts.

### **4.1 Community**

Community is a regularly used concept in modern day language. Yet, community can be a difficult and diverse concept and it has been the object of scholarly debate for several decades. Many discussions seem to revolve around the definition of community (Bell & Newby 1974; Delanty 2010). Some examples are: norms and values shared by individuals, reciprocity and mutual assistance, geographically bonded individuals and like-minded individuals (Bruhn 2005:214). These different definitions are often used interchangeably, which has resulted in vagueness around the concept of community (de Koster 2010:4). Nevertheless all definitions imply that communities are characterised by existing relationships between a group of individuals. These relationships go beyond the causal and are based on some commonality that distinguishes a specific community from other groups of individuals implicating a sense of belonging (Bruhn 2005:11; Delanty 2010:xiii; Wilbur 1997:8; Willson 2006:22).

In the past, the commonality on which communities were based often referred to geographical proximity. But with the rise of the Internet, communities are no longer bounded by geographical closeness and commonalities can be sports, jobs, demographic characteristics and other shared interests. The migration of communities to the Internet has had a major impact on the conceptualisation and functioning of communities since traditional characteristics were no longer a fundamental feature (Cavanagh 2007:102). The emergence of these online communities will be discussed in the next paragraph.

### **4.2 Online community**

The Internet has accelerated theoretical debate around the conceptualisation of communities (Cavanagh 2007:102) After the virtual communities first emerged in the 1990's the term rapidly became a buzz word for any online venue where members could communicate (Rheingold 1993). This resulted in sociological discussions around the question whether the concept of community could be extended to include communities on the Internet (Preece 2001). The discussion is mostly due to the interest in online communities from different academic disciplines. Ethnographers focus on the roles and activities of (groups of) individuals, technologists are more concerned with the structure of the software underlying the community while sociologists tend to focus on the community relations (Souza & Preece 2004:580). Much research therefore addressed the definition of online communities and the

characteristics that online venues had to incorporate in order to be characterised as a community (Preece & Maloney-Krichmar 2003). Examples of key elements are: shared values, mutual commitment, common interests, shared purpose and norms and policies (de Koster 2010:5; Preece 2000:8-9).

Several authors discuss the significance of community behaviour in the sustainability of an online community. The most basic activity to sustain a community is active participation through the creation and consumption of content. This refers to the generation of messages and the reading and reacting to those messages. Without a basic level of participation and interaction the beneficial aspects of a community – such as social capital – cannot be achieved. The importance of interacting and active members in communities was also emphasised in the dynamic view of social capital in the previous chapter. According to Butler et al. (2007) individuals who have a formal leadership role within a community are most likely to assure this basic level of participation. These individuals will spend a substantial amount of time trying to build and sustain a community. Other participants may also qualify as active participants, depending on their motivation for participation. Some participants are active because they want to gain access to otherwise unavailable information. Other participants want to benefit from the community ties that they can establish on an online community (Butler et al. 2007). The motivations and levels of participation that are attached to that may also be observed in the empirical part of this thesis, since motivations and goals will be assessed. The amount of time that is invested in the community will also be assessed and may be indicative for the level of participation.

The motives for participation and the time spend online may also be determined by the advantages associated with online communities. Online communities have several advantages over traditional support groups that meet face-to-face. The biggest advantage may be that members of the online communities are able to communicate from their own home (Weinberg et al. 1995). For many patients this is their only way of communicating with other patients because their illness leaves them unable to physically attend meetings. In addition online communities are better able to assemble a group of individuals with similar issues, because geographical boundaries are no longer an obstacle (Wright 2000:56).

### **4.3 Community ties**

The relationships between individuals are sometimes referred to as ties, network ties, social ties and community ties. These terms are often used interchangeably, what has resulted in vagueness surrounding the meaning of the different ties. What is meant by the specific concepts seems to depend on the operationalisation and sometimes the preference of the authors. Nevertheless, ties are essential in the sustainability of a community. The ties

facilitate interaction that is established through messages between community participants (Butler et al. 2007).

According to Granovetter (1973:1361) tie strength is a combination of “the amount of time, the emotional intensity, the intimacy and the reciprocal services which characterise the tie”. This results in a robust categorisation of strong, weak or absent ties. Strong ties are often associated with close friends and family while weak ties refer to acquaintances. In his work, Granovetter emphasises the cohesive power associated with weak ties. He argues that “ideas, information and influences that are socially distant” from an individual are more likely to diffuse through weak ties (Granovetter 1973:1370-1371). These socially distant resources are therefore rarely obtained via strong ties as the individuals with which one has strong ties often possesses similar resources. This is relevant for online communities as the Internet can be used to create new (weak) ties with virtual acquaintances (Pénard & Poussing 2010:570). Patients can thus use the Internet and online communities to create new ties with virtual acquaintances. Granovetter suggests that weak ties may be most beneficial for patients because these ties allow the diffusion of socially distant – and therefore otherwise unavailable – information.

Network ties are also used commonly, especially in studies using network theoretic approaches, such as network analysis. Research using network analysis is mainly concerned with the content and governance of network ties as well as network structure (Hoang & Antoncic 2003). Nonetheless, social and community ties are used most often in relation to social capital. Social ties seem to refer to all social relationships between individuals, groups and communities. Lin (1999) is one of the authors that uses the term social ties which he links to social resources. Nevertheless, social ties can relate to all social relations between individuals. Using the term community instead, implicates a sense of belonging. Community ties then refer to the relations between individuals of a certain community. Since this thesis will specifically focus on online migraine communities and the ties between individual members, the term community ties is most appropriate. If social ties would be used, relations outside of those online migraine communities could also be included, but those other social ties of individuals will remain outside of the scope of this thesis.

#### **4.4 Resources**

Social capital was previously defined as: “resources embedded in social networks, accessed and used by actors for actions” (Lin 2001:25) In general, resources refer to a feature that individuals or groups can draw upon, such as information, money and status. Lin’s (1982) definition of resources as: “material or symbolic goods” provides some guidance but the concept remains abstract. Lin (2001:44) argues that social capital is contingent on resources embedded in direct and indirect ties. Not all those resources are available for individuals by

possession, rather they are accessible through community ties. These resources are embedded in the ties between individuals and can be material goods like money and houses, but also symbolic like reputation, education, associational membership and fame (Lin 2001:43). Both material and symbolic goods are characterised as acquired resources, because they have been obtained during life. Ascribed resources on the other hand, are resources an individual is born with such as race or gender (Lin 2001:55).

There are numerous resources that individuals can draw upon in relation to social capital. Some examples of possible resources in relation to social capital on online communities may be helpful in providing analytical directions and to give the reader some practical understanding of the concept. Many resources relate to the information available on online communities. Kivits (2004) for example argues that participants are mainly concerned with finding experiential knowledge that goes beyond pure medical knowledge (Kivits 2004:517). The Internet and online communities consist of different information resources that can be utilised by patients. This multiplicity of resources allows for the personalisation and contextualisation of health information that doctors often fail to provide (Kivits 2004:515; Kivits 2006:273).

Drentea & Moren-Cross (2005) in their research on online mother communities mention formal and informal instrumental support that refers to practical and medical information. Ferlander (2007) also recognises this informational support that consists of giving and receiving advice and information. Ferlander (2007:116) argues that this information may lead to solutions for particular problems. This may also be observed on online migraine communities because patients can discuss different treatment options or home remedies. Ellison et al. (2007) relate useful and non-redundant information to the well-being, satisfaction with life and the self esteem of individuals. Pénard & Poussing (2010:572) mention valuable information, happiness, self esteem and better living conditions in relation to resources and social capital. Greene et al. (2010) distinguish personal clinical information and disease specific guidance and feedback as information that is frequently requested or provided on health-related FB communities.

Other examples of resources can be related to the support that is available on online communities. DiMaggio et al. (2001) mention reinforcing existing behaviour patterns, companionship and social support as frequently found resources of (online) social capital. Greene et al. (2010) evaluated the content of communication on online Diabetes communities on FB. They found that members of those communities used FB to receive emotional support, engage in community formation and provide interpersonal support. Ferlander (2007:116) also recognises social support as a resource associated with social capital. In her discussion of key elements of social capital she provides a categorisation between different types of support. Social companionship is characterised by individuals who



spent social or leisure time together. This can for instance be observed on online communities when participants discuss their daily life with each other. Instrumental support indicates practical help like money or labour and may be less relevant for the online communities. Emotional support includes feelings of empathy, caring and trust and is likely to be observed on online migraine communities because participants share similar experiences. This emotional support is also a frequently observed activity by Drentea & Moren-Cross (2005) and is based on norms of reciprocity. The same authors observed community building and protection in the sense that norms of support and mutual respect and understanding are maintained and enforced. Finally social capital may provide resources like moral support that can affect the health of individuals. According to Poder (2010:4) moral support can help to counter feelings of vulnerability, insecurity and abandonment. Because individuals have a support system and are less likely to be abandoned, they are better able to reduce the frequency of episodes characterised by stress or depression. This can help limit the emergence of chronic or infectious diseases.

There are different approaches to measuring these resources (Lin 1999:36). The first approach focuses on network locations and the distance of an individual from a strategic location. Such a location is hypothesised to give access to for instance diverse or more information. Indicators are network intensity, structural holes, network bridges, and network reciprocity (Lin 1999:37). Granovetter's (1973) strength of ties theory is an example of this network location measurement technique. The second approach is concerned with embedded resources that are divided into network and contact resources. The network resources are embedded in an individual's own network and are readily accessible. Contact resources on the other hand, refer to resources that are embedded in contacts and have to be mobilised in order to be used (Lin 1999:36). Indicators for network resources are the composition of resources and the range of resources, while indicators for contact resources are the authority and occupation of one's contacts (Lin 1999:37).

## 5. Methods

This thesis explores social capital in online migraine communities, which is a relatively unknown research topic. To gain insight in the way community ties on online migraine communities provide migraine patients with access to resources, an explorative and qualitative research format has been used. The case study provided a format to analyse specific case characteristics and enabled the inclusion of the experiences and interpretations of migraine patients (Gillham 2000:11-12; Stake 1995:8; Swanborn 2010:12-14). Migraine was chosen as an empirical case because of the individual character and trivialisation of the disease that often results in inadequate care and a lack of support and understanding for migraine patients (WHO 2004; Winter et al. 2011:148).

Two online migraine communities were selected. Inclusion criteria were presence on FB and daily activity at the point of selection in December 2011. Presence on FB was essential because this thesis focussed on FB communities given that FB is increasingly becoming part of social life, traditional support groups are gradually relocating to FB and health-related FB communities have been up-and-coming. Daily activity was essential to ensure a substantial amount of data and to be able to address patients that were active online participants.

'Migraine sufferers' is a FB community that has 2649 members and was selected because it was initiated by patients and not by a company, governmental organisation or health professionals. Communities initiated by patients provided interaction between patients, while conversation on communities initiated by companies, governmental organisations or health professionals was limited to comments from the administrators. Since this thesis will focus on the community ties between individual patients, a community initiated by patients was selected. As a second case 'migraine.com' was selected. This website is aimed at migraine patients and caregivers by providing information, tools, expert discussion and forums (Health Union 2012). It also has a FB community with daily activity. This means both cases have active FB communities, but migraine.com is complemented by a website that offers a different infrastructure to migraine patients and could facilitate different communication than migraine sufferers (Seawright & Gerring 2008).

Three different research methods were used to get a complete case description and to increase the validity due to method triangulation (Lewis & Ritchie 2003:275-276). Firstly, document analysis was used to get background information and to frame the research site (Bowen 2009). The documents that were analysed were privacy policies and business statements and goals. As a second method, observations were carried out to gain insight in the activities of migraine patients within the research sites. Online observation allowed for the textual observation of participant interaction and the reality they construct (Markham

2004:113-116). Because the observations were carried out online members did not notice intervention, which eliminated the biggest disadvantage attributed to observational techniques (Flick 2009:225-226,282 Mann & Stewart 2000:84). The observations were carried out from 01-01-2012 until 31-03-2012 on both FB communities. In that same period observations were carried out on the forum of migraine.com. During the observations there was a focus on specific characteristics that were documented. The language that was used, the topics that were discussed, the number of posts on a specific topic and the activity of each participant were the main characteristics documented.

As a final method e-mail interviews (e-interviews) with members of the two communities were conducted (e.g. Bampton & Cowton 2002; Mann & Stewart 2000:126-159). Contact was made with the administrators of both communities. Migraine.com placed a research call on their website which led to twenty-two members willing to participate in this research. Six of these members were excluded from the research because they did not react after the first e-mail or only reacted once. This exclusion of respondents due to insufficient response led to sixteen participants from migraine.com. After several failed attempts to contact the administrator of migraine sufferers, several research calls were posted and led to email contact with six members that were willing to participate. Five of those participants were active on both communities which enabled the direct assessment of differences between the two communities. All respondents were female and were between the ages of 26 years and 58 years. Most respondents were located in the USA, only three participants were located in Australia, the Netherlands and the United Kingdom.

The interviews were semi-structured and included four to thirteen e-mails between 13-03-2012 and 07-05-2012. This recurring e-mail contact allowed for regular episodes of questions and answers so that statements and conclusions could be checked with respondents (Bampton & Cowton 2002). The semi-structured interviews also created an opportunity to address theoretically deducted themes while incorporating the interpretations of participants (Flick 2009:156-161; Mann & Stewart 2000:75). Finally the e-interview allows respondents to transcribe their own answers in their e-mails, so that the research data are available in the precise language used by respondents (Bampton & Cowton 2002).

The data collection and data analysis were intertwined and enabled the researcher to complement and check data and conclusions. Interpretations of the researcher were checked with the respondents to avoid presumptions of the researcher. Thematic analysis was applied that was based on themes derived from the research questions and the data itself (Flick 2009:374; Joffe & Yarley 2004). The answers of different respondents to similar questions were coupled and were then coded to one of four themes: motives and goals, investment, (meaning of) resources and community ties. The most important results of each theme are discussed in the next chapter.

## **6. Results**

In this chapter the key findings from the research will be displayed. The motives and goals for participation in online migraine communities will firstly be outlined, followed by the investments made by participating members. Then the resources available on online migraine communities and the meaning participants attach to these resources will be discussed. Finally the community ties between members of online migraine communities will be characterised.

### **6.1 Motives and Goals**

Before looking into the resources available to community members and the nature of the community ties, the goals and motivations for participation have to be specifically addressed because these elements are often presupposed by researchers and almost always attributed to information supply and social support (de Koster 2010:12,32).

#### ***Information***

Information supply indeed proved to be a main motivator for participants to subscribe to online communities in this research. One respondent explains why she finds the information from online participation important:

“When my migraines became chronic I went on a crusade to learn everything I could about my condition. The internet was an invaluable tool for this, even though it meant wading through a lot of material. Originally I was not looking to become part of an online community; I was just looking for current and accurate information about migraine”  
(Respondent A).

This indicates that for some participants information supply is the main motivator for online participation and that online communities provide information that is valuable for participants. Respondent A's comment suggests that 'becoming part of an online community' is not necessarily the primary goal, but may be a secondary benefit because of the given interface where the information was found – in this case, the community platform. Participants looking for information online were hoping to find more, other and new information (Respondents A; B; D; F; H; O; P; Q). The online communities – especially migraine.com – provided a platform where patients could find these types of information.

Some participants were searching information online because they were not receiving enough information from their physician or because they felt their physicians were not well informed themselves (Respondents A; B; D; F; H; P). Neurologists or headache specialists were considered more knowledgeable, but often did not have enough time to discuss treatment options or explain information. As one respondent indicates:

“I discovered most family practice doctors really do not know very much about migraine. I would ask a question and realize by their answer that they did not have a very extensive knowledge base. This is not such an issue with migraine specialists, but [...] since most doctor visits are so short (15-20 minutes is pretty standard) there never seems to be enough time to discuss treatment options at length or get detailed information or explanations to really educate oneself about one’s health concerns” (Respondent A).

Like this respondent, many participants felt that online communities kept them updated and provided new and accurate information that doctors could not provide them with (Respondents A; F; H; O). This indicates that respondents were dissatisfied with the care they received from both their physician and neurologist or headache specialist. Respondents need either more time or more information from their doctors. Through their online participation many respondents were hoping to fill this knowledge gap created by the inadequate care they received from their doctors.

Other participants were looking for information online in order to be more well-informed *before* going into a doctor’s visit (Respondents F; O; Q). One respondent says: “I am able to compare my treatment and the treatments of others, which makes me a more informed patient when I visit my own doctor” (Respondent F). This is supported by comments placed on the online communities in which appointments with doctors were mentioned. Participants were asking for particular information and mentioned they needed the information to discuss treatment options or check whether particular information was applicable to them. Comments like: “I see my neurologist tomorrow”, “...scheduled to go back Thursday”, “...because I have an appointment with” and “I have an appointment for next week” were frequently observed and reflect that many participants used the information found online in their contact with doctors.<sup>2</sup>

Another element of the information supply motivation was that by participating in an online community participants felt they could benefit from the experiential information from fellow patients. One respondent indicates that the experiences and home treatments of others made her try new things. In relation to taking magnesium supplements for migraine prevention she says:

“I tried it and wow: it actually does help and none of my doctors have ever mentioned it in more than thirty years of treatment. I do not always try everything or the stuff I do does not always work for me, but there is discussion and real personal answers out there that I would not get if I did not get online” (Respondent F).

There were numerous conversations like this that discussed home remedies and alternative products which proved to be helpful for participants. Examples were sunglasses that

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<sup>2</sup> Migraine sufferers and migraine.com FB page.

completely block sunlight, migraine caps that keep the head cold and beverages with caffeine (Respondents H; Q). This experiential information is a type of information that differs from straightforward medical information that doctors and medical websites can provide. It provides patients with new perspectives and ideas to cope with their migraines. Moreover, experiential information often takes the form of practical products or steps that patients can undertake in order to reduce their migraine burden. This practical help would not be (so easily) available to participants if they did not participate in an online community because physically bringing together a group of migraine patients can be difficult given the nature of the disease. The availability of experiential information and practical help can thus be seen as a motivation for online participation since this resource is hardly available offline.

### ***Social support and interaction***

Another big motivation for participation in online migraine communities was social support and interaction. Many participants mention their social isolation because they are often unable to participate in social gatherings due to migraines. As one respondent indicates: “Migraines can be isolating. I often have to cancel on friends and I cannot be as social as I would like to be. This website helps me to feel like I am having some kind of interaction” (Respondent B). Another respondent explains why migraine patients are unable to be as social as they would like to be: “I was experiencing no social life outside of work. I would come home from work with a migraine at night and be laid up mostly every evening and all weekends; trying to recuperate so I could make it through the next work week” (Respondent E). Although this respondent indicates that work and migraine prohibited her from social interaction, other participants experienced social isolation due to migraines and the exact opposite.

Participants who were laid off, had to stop working or had to work from home due to migraines missed the contact with colleagues, which for some participants was the only social contact they had (Respondents H; P). As one respondent says: “When I went on disability, I became so lonely and depressed, that I found the migraine support sites very helpful” (Respondent E). Many patients cannot go out of their home much because of having a migraine or the fear of triggering one (Respondent H). Therefore online communities give participants a unique opportunity to interact with others without physically attending social gatherings. As one respondent indicates: “...it facilitates connection even when or perhaps especially when, you feel physically lousy and may be unable to participate in ‘regular’ life activities” (Respondent A). This means that for some participants online participation is their only method to achieve social interaction with individuals that do not live with them. Without the ability to communicate from their home, some participants are unable to meet new people but also to keep up with established contacts. Online communities therefore create an

opportunity for migraine patients to establish social interaction. This interaction can be extremely important for patients because they can feel isolated due to their migraines. The inability to work or participate in social gatherings, as previously discussed, can prohibit social interaction and create feelings of isolation. Online communities can counter these feelings of isolation, vulnerability and insecurity.

Furthermore, online migraine communities have the added benefit of not only bringing together participants, but also bringing together participants with similar issues. This way participants are not only able to interact but also able to interact with individuals who suffer from the same disease. This can be another motivation for online participation because many participants find it difficult to discuss their migraines with friends who live nearby but do not have migraines. Participants also mention that they do not know many people in their neighbourhood or city that suffer from migraines. As one respondent indicates: "I have tried locating an in-person migraine support group near my town several times in the past and I have never been able to find one. So the online community bridges that gap" (Respondent A). For many participants online communities are therefore the only way to meet other migraine patients. The added value of this interaction between migraine patients will be further discussed in the paragraph about resources.

## **6.2 Investment**

Online participation consists of different components and differs between participants. In this paragraph the time spent online and the activities on the online communities are discussed.

### ***Time***

The most obvious measure of investments by participants is the time spent on the online community. Participants spend a minimum of fifteen minutes a day on the online community, which is sometimes triggered by message alerts. For migraine.com these alerts are e-mail newsletters and tweets that report new articles and stories. Members of both FB communities can be alerted by a message indicating that someone commented on their post. Migraine sufferers additionally has a button in the FB menu page indicating the number of new posts since the last visit.

At the other end of the spectrum is the maximum time spend on the online communities. One respondent says: "All my time is spent speaking with migraine people. Either support or raising efforts of some type. As long as I am capable I am here. That could be all ten to twelve hours. If I can see and stand being at the computer I am doing stuff" (Respondent D). This particular respondent participated in communities and was the administrator of several communities herself. The difference between the minimum and maximum time spend online indicates that there is a big range between individual

investments in the online communities. However this difference in individual investments is not necessarily an issue on online communities because even small investments can be valuable. This will be explicated in the rest of this chapter.

### **Information**

The time spent on online communities is divided across different activities. The main activity is information gathering through articles and posts. Some members only participate in this activity and as such are not visible as participants for fellow members. For most participants privacy issues are the main reason for remaining 'invisible'. Especially the public nature of FB is concerning for many patients. One respondent shares her concerns:

"I do not post personal things on migraine sufferers which is a public group and will come up in Google searches. [...] The fact that the information (whatever I post) is publicly available is concerning, because it means future employers will be able to see it"  
(Respondent M).

Another patient expresses different privacy concerns:

"I do not like to post because then [the posts] show up on my feed. I feel like I am still 'in the closet' with my friends and do not really want them to be all in my business about how bad my migraines have gotten. Once you tell everyone they keep asking how you feel every day and it gets hard to tell them that you are not better and may not be better for a while" (Respondent B).

Thus many participants have privacy concerns, but they may include different aspects of the online participation. Some have concerns regarding their employer, others regarding their friends or family and some have privacy concerns in general as discussions can come up in Google searches (Respondents B; M; O).

The concerns that these participants express can be linked to the technical possibilities and infrastructure that underlie both FB and Google. In the case of FB, all activities of the participant are documented and are presented to their lists of friends. This makes it impossible to keep parts of the 'online life' - such as the participation in migraine communities – private or separated. Moreover, Google is able to scan the entire web and display web content that refers to a particular person. Although these technical applications were originally created to increase connectedness and enhance searching convenience, they are now creating barriers for patients to fully participate online. These applications may therefore be prohibiting the production and exploitation of social capital on online migraine communities on FB.

For many participants the privacy concerns prohibit them from interacting with other participants. The participants indicate that they feel more comfortable on a private forum.



Nevertheless, many participants feel they have to be active on FB. As one respondent indicates: “I have been having issues with privacy, because most of FB is not private. But it is the only place that is really active anymore” (Respondent M). This highlights the considerations about investments and outcome that many participants have to balance when participating in an online community on FB.

The migraine communities on FB have a higher degree of activity and therefore have more interaction. This interaction is essential in the realisation of social capital. The FB communities therefore hypothetically have more resources available for individual participants. However, these communities demand a bigger investment from participants in terms of privacy. For some participants the investment of privacy is not such an issue, because they value the resources that can become available more or because they do not recognise the consequences of online participation. Some participants however are not willing to invest parts of their privacy and choose to seek communities with a private character and thus accept downsides such as lower activity and/or fewer resources they can draw upon. This means participants have to consider the investments they are willing to make in order to draw upon particular resources. This makes the choice for a particular online community deliberate since it requires personal consideration about input and output.

### ***Interaction***

Another activity that participants invest their time in is sharing their migraine story. During the observations phrases like “have been battling”, “have been having” and “I have suffered” were frequently observed and were followed by a personal migraine story. Most of the personal stories shared, were by new members who wanted to introduce themselves. One respondent also shared her story after registering for the migraine.com FB page and said: “I have never been a part of any support group for migraine before. I shared my story which really gave me a sense of freedom. I was finally letting people in on what my life has been like and what I deal with on a daily basis” (Respondent F). The online community thus creates an environment where participants feel comfortable to share their personal stories.

A reason why participants share their personal stories might be that they often trigger reactions from participants that have a similar story. As one respondent indicates: “If I see someone post a question or story that personally connects with mine I encourage [...] them. I [...] find that when I try and help someone else get through a tough day I feel better too” (Respondent F). Like this respondent most participants reply to a story or give a like<sup>3</sup> and thereby express their involvement in the online community. The expressions of involvement

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<sup>3</sup> FB has a ‘like’ button that users can press to indicate they like a certain message, photo or page.

can be of particular importance because some participants may feel frustrated by not getting a response. As one respondent indicates:

“When I first started posting and answering other people's questions online, I was very disappointed by the fact that few people would reply and acknowledge or thank you for your response. I guess I thought it would be more like holding a conversation, with several exchanges back and forth. I have since learned not to expect a direct response and to think of it more in terms of putting a thought or suggestion out there and trusting that anyone searching for the information will find it and make use of it at some point in time. Then when someone does respond, it is quite a treat” (Respondent A).

This indicates that small expressions of involvement and ‘visibility’ are highly appreciated on online communities and may be a reason why participants feel comfortable to share private and personal experiences online.

Another reason might be that through the collective sharing of personal migraine stories, participants are able to read the stories of others that relate to their own. Realising that other people have similar problems makes participants feel connected and understood. As one respondent indicates: “I went to the site and read some stories from people and I instantly felt relief. There were people out there who understood and suffered like me” (Respondent F). This indicates that shared experiences play an important part in understanding, recognition and support. These features will be further discussed in the paragraph about resources.

### ***Social support***

As previously discussed, social support is a motivation for online participation and can therefore frequently be observed on the online community. While getting social support will be discussed later in this chapter, current focus is on the support that is provided by participants, as investments are discussed here. These do not need to exclude each other, as one respondent says that by interacting with fellow members, she feels she is helping others while helping herself (Respondent F). However, giving social support requires at least a small investment of time. As one respondent puts it: “I am open to helping anyone who needs it even if it’s just a short message saying I understand because I’ve been through it” (Respondent F). Participants may express their social support in different ways. Some check up on fellow members while others place reactions with encouragement and advice (Respondents E; Q). In general, members support each other by little gestures and messages. This means that social support online can be provided even by small time investments.

### **6.3 Resources**

Participants recognised different resources available to them on the online communities. These resources are connected to the topics discussed in the previous paragraphs and can be divided into information, interaction and support resources.

#### ***Information resources***

Information resources are the first category that participants can draw upon. As one respondent says: “I continue to learn more about how to successfully manage this disease by reading the info[rmation] on the online migraine sites and feel very lucky to have had these resources so readily at hand” (Respondent A). Especially migraine.com was praised for their articles. As one respondent says: “I love the up-to-date articles about new med[ication], procedures, disability issues etc. It is a one stop place where I can find information on all migraine related issues!” (Respondent F). This respondent called it a ‘one stop place’ because migraine.com offers different perspectives on migraine treatment and coping with migraine in daily life. The website accommodates information from doctors, patient advocates, legal experts and caregivers. The doctors and associations that are attached to the website give it authority and create an infrastructure that participants recognise as trustworthy (Respondent B). The non-medical perspectives on migraine.com provide information that is understandable, easy to use and practical. This type of information complements the straightforward medical information and is also a type of information that cannot easily be found elsewhere online. Migraine.com therefore provides a whole range of information resources and is for many participants a ‘one stop place’.

Migraine.com was also praised for their up-to date information and articles. This seems to be so important to participants because they often feel their doctors are not up-to-date, as was discussed in the first paragraph of this chapter. As one respondent indicates:

“Having a community about migraines offers me a lens into the migraine world. I am not a doctor. I do not know a lot about current advances in migraines. Going to doctors local to me I have found that they can lag with information. A group like migraine.com offers me a place to get lots of information from around the world all about migraines” (Respondent H).

By being informed themselves, participants feel they can be in charge of their disease and become more empowered. One respondent mentions why she values up-to-date information: “Basically to be more informed so that I can go to my doctor and feel more educated about my illness and ask about latest research and treatments and feel more in control of my illness rather than it controlling me” (Respondent Q). This indicates that the opportunity to find up-to-date information online is an important factor in the empowerment of

patients. Many participants value this opportunity for empowerment, which is exemplified by the next quote of a respondent:

“Ultimately I believe I am fully responsible for my health care and I cannot make wise decisions unless I am fully informed about all options available to me. I am not going to accept a doctor just handing me a prescription without my understanding why, and agreeing with how he/she came to that decision” (Respondent A).

It can be concluded that many participants recognise the opportunity to find up-to-date information online and value this because it enables them to feel more in charge of their disease. Migraine.com provides a platform of information resources that can be accessed by participants and helps them counter the historically asymmetrical doctor-patient relationship. It therefore enables them to take up their role as more empowered patients because the information found online helps them to become more in charge of their disease.

Besides information being up-to-date, other types of information could be distinguished. Much of the information found online was medical information that provided participants with more understanding of their illness or therapy. Searches that included medical information were often aimed at specific topics. Participants were hoping to find information suited to their particular pathology such as chronic migraines, migraines with auras and hormonal migraines. As one respondent indicates: “[...] because I am menopausal and my migraines are mostly hormone triggered, my searches often include those topics” (Respondent A). Migraine.com supports this by providing information on their website that is archived on specific variants, triggers, symptoms and treatments of migraine (Health Union 2012).

Another important type of information consists of experiences, contextualised and practical information. Experiences from fellow patients provided participants with information that differed from the straightforward medical information, but proved to be very beneficial. One participant gives an example of the benefit of experiential information in relation to medication: “I had a bad reaction to [drug X] and it were not the doctors that helped me. It was the information I found online posted by normal folks and [...] the community attached to that” (Respondent H). Another respondent also emphasises the benefit of experiences of other participants:

“Lots of information [is available] on the medications people [take], the side effects, [whether] it has helped people and what to expect. This has been really helpful when I started taking medication for my migraines as I already knew about the medications, what they did and what to expect” (Respondent Q).

This indicates that online communities provide an infrastructure where experiences can be exchanged which gives participants the ability to seek practical information. The practical

information can only be provided by migraine patients themselves, which points out the added value of the collective. A collective of migraine patients can almost only be established online due to the nature of the disease and the geographical spread of patient, as was discussed earlier. Online communities therefore provide a unique opportunity to bring together experiential and practical information resources.

### ***Interaction resources***

The second category of resources emphasised by participants was interaction. Communicating with fellow patients gave participants the opportunity to get feedback, advice and guidance which made participants feel connected. During the observations many conversations consisted of participants posting questions and asking for (similar) experiences, advice, suggestions and input. Phrases like “any input”, “need guidance”, “any suggestions” and “grateful for any feedback” were frequently observed. A respondent emphasises this:

“When myself or anyone is having a bad day with a migraine and needs help to get through it, they will help with supportive comments. They may help solve a problem you might be having at home but you cannot think due to a migraine. If you are out of ‘rescue medications’ they will offer suggestions on things you can do to get you through the day” (Respondent Q).

The feedback and advice was especially appreciated because it came from fellow patients who could relate or had experience with certain drugs or therapies (Respondents E; H). One respondent even says: “For me, the most valuable thing about online communities is that you can find someone who [...] has experienced what you are going through very quickly” (Respondent H). Participants recognised that the online community provided them with an opportunity to express their feelings to people who shared the same experiences (Respondents A; E; F; Q).

### ***Support resources***

Finally participants emphasise that support is a resource they can draw upon. As one respondent says: “There is [...] a general feeling of support from the community as a whole that makes a big difference” (Respondent A). Support seems to consist of different elements such as understanding due to shared experiences. This understanding can be a great supporting factor for participants, as one respondent says:

“With migraine.com being on FB, I am able to speak to other migraineurs daily and find a place where I can share a laugh and a smile or just vent with people who understand. By having online friends who understand I am better able to express my feelings and find ways to deal with migraine life” (Respondent F).

By interacting with fellow patients who have been through similar experiences, participants feel understood. Respondents indicate that heartfelt replies, supportive comments or small messages help them feel understood. One respondent points out that simple things like “hugs and prayers coming your way” can help her get through a rough day (Respondent F). In this case the respondent indicates that these small comments are so supportive because they are coming from people who truly understand. Respondents indicate that support from family and friends is different than support from fellow patients. Friends and family, although sympathetic, are never able to fully grasp the experience of having a migraine. One respondent denotes the subtle difference between empathy and understanding: “Of course they hear me talk about my migraines but they do not see it. They say it must be terrible so I get the empathy but it is not that same as getting the support from fellow sufferers” (Respondent Q).

Support also consists of encouragement because it can make participants better able to cope with their illness. As one respondent indicates: “Migraine.com has taught me so much about this disease. Ways of coping with it, finding hope and encouragement through fellow migraineurs that I would have never met had it not been for migraine.com” (Respondent F). This respondent indicates that these online communities are key in finding encouragement and support. Many other respondents also indicate that they find encouragement on online communities (Respondents A; E; F; Q). One respondent discussed how important encouragement from fellow members was for her, when she was extremely dissatisfied with her physician that would not refer her to a neurologist: “I told the group and they encouraged me to change doctors. They really empowered me, made me feel like my health really is important. I ended up getting a fantastic GP who referred me to a really good neurologist and I am starting to feel better” (Respondent Q). This indicates that the support and encouragement from the online community can be a valuable resource for participants. The support and encouragement from fellow patients cannot easily be found offline due to the nature of the disease and the geographical spread of participants, which makes online communities a unique place to find encouragement.

The recognition of particular issues and problems can also give support to participants. Having a disease that family and friends cannot understand, makes participants feel lonely. The interaction with fellow patients and especially having others validate their symptoms and issues, makes participants feel ‘normal’ (Respondents H; I). As one respondent states: “So often I just feel like a freak with a disorder no one can see. In the community at migraine.com, I can feel supported and validated” (Respondent H). Another respondent supports this: “We all need to feel validated and know we are not crazy. [...] I think the need to be accepted and belonging to something that accepts you is something we all want deep down” (Respondent D). Besides feeling ‘normal’, the interaction with fellow members may

also provide patients with hope. Respondents indicate that reading the stories of others also gives them hope, since 'success-stories' indicate that there is always a chance things might improve (Respondents F; Q). The community and its positive values are therefore important to the individual. It is a place where participants can interact and find stories of fellow patients that have found appropriate treatment or coping strategies for their migraines. This provides participants with the hope that they may also find relief in the future.

#### **6.4 Community ties**

The community ties within the online communities can be characterised based on a three point scale that includes: no ties, superficial ties and close ties.

##### ***No ties***

At one end of the scale are the participants that indicated they experienced no ties between participants on online communities (Respondents M; O). Most of these participants however, did not post or comment on the community and remained 'invisible' for other participants. This may be a reason why they did not experience any ties between participants. Moreover, these participants were not looking to become part of an online community with ties attached to that. As one respondent for instance says: "I have not formed any connections or friendships. I use migraine.com just for information" (Respondent O). This respondent thus only uses the online community for information and does not draw upon the interaction and support resources. Others may not tap into these resources because of other reasons such as the privacy issues that were discussed earlier.

##### ***Superficial ties***

One step further up the conceptualised scale are the superficial ties. According to respondents these ties indicate a sense of recognition between participants (Respondents F; M). This recognition is established because participants read each other's stories and posts regularly so they are aware of each other. This contact may also include short interactions between different participants. One respondent therefore describes these superficial ties as: "acquaintances or people I talk to every now and then" (Respondent F). Conversations between participants with superficial ties are often centred around medical issues. During the observations many conversations revolved around medications, symptoms, doctors' advice, triggers and therapies. Some personal information was shared but this was mostly superficial information or migraine related information such as age, migraine history and personal feelings towards migraine. This observation is supported by a respondent who indicates: "On migraine sufferers it is often about medical [issues], but sometimes it is [more] personal" (Respondent M).

### **Close ties**

At the end of the spectrum are the close ties that are often referred to as (close) friendships. These friendships include close ties between only a few participants. As one respondent says: "I have a small group of women I have become close to (Respondent D). These small groups of online friends often share several commonalities that bond them. As one respondent indicates: "[They] have become regular correspondents with whom I share [...] an ongoing conversation [...] – mostly due to our being female, married and the same age" (Respondent A). Another respondent shares this argument and says: "We are all married mothers in our forties and fifties, so that was a common bond" (Respondent E). These commonalities are different from the traditional common factor of geographical proximity.

Geographical proximity is however still a factor that is associated with close ties and friendships since it was addressed by many respondents. Examples are: "We live in various parts of the US and nowhere near each other", "...even though we live all across the country", "We just live in different parts of the country" (Respondents E; F). This geographical proximity seems to be addressed because participants have a desire to meet their friends in person. This is expressed by respondents through comments about not having or actually having met their online friends in person. As one respondent indicates: "I have one friend who will be vacationing near where I am this summer and I hope to meet her face to face" (Respondent F). And another respondent says: "I have actually recently met a few of the people in person" (Respondent Q). Participants with close ties thus have a desire to meet their fellow participants in person. This seems to be due to the friendship they have established and the need to incorporate features of conventional friendships such as face-to-face contact.

Another feature of the close ties is the range of topics that is discussed. While the conversations between participants with superficial ties are more concerned with discussions on migraine, conversations between friends with close ties include a wider range of topics. As one respondent indicates:

"They have become [...] very dear friends, [...] sounding board, true friends and we have seen each other through some deep emotional and physical events [...]: the death of one of our group, deaths and severe illnesses of family members, our own hospitalizations, depression and anxiety, issues with our children, husbands and other family members, cooking, medical issues other than migraine and everyday events. You name it. I know the other three women very well now: their life stories, families, highs and lows and we share much of our day-to-day life" (Respondent E).

From the above it becomes clear that all parts of life are discussed within these close ties. A reason why participants with close ties discuss everything with their online friends may be that their whole life revolves around migraines. As one respondent explains: "There is



no part of our life that is not effected by migraines, so there is no topic that is taboo. Whatever is going on in our lives comes back to migraine, our everyday life is migraine” (Respondent D).

The range of topics that is discussed may also be indicative of the closeness between participants. When a wider range of topics is discussed, participants might have closer ties. In order to establish these close ties and discuss a wide range of topics, participants have to know each other quite well. This means that they have already invested a substantial amount of time into their relationship so that this particular degree of involvement is established. Many participants therefore feel these close ties (partly) represent a conventional form of friendship. As one respondent says: “We discuss everything from treatment to how to take care of a family, to just what ways we enjoy life and what activities we still enjoy and those we cannot because we have migraine. We share joys and sorrows just like real friends do” (Respondent F). One respondent even goes beyond this argument and says about her online friendships: “I feel closer to them sometimes than my friends that live in my town because they do not have migraine. It is a really tough disease to live with and understand if you do not experience it yourself” (Respondent F). This indicates that online community participation can create close ties that can take the form of conventional friendships. Because conventional friendships are sometimes hard to maintain for migraine patients, the online communities create a unique opportunity for participants to maintain and establish friendships.

Because participants share personal information with each other, the contact between participants with close ties is often redirected from the online community to private messages and forums. Some participants stay active on the same website they met, but change from a public to a private format and only correspond through private messages (Respondent A). Others relocate as a group from a public to a private forum and therefore change locations. The considerations for changing locations is shared by a respondent: “I [am] able to share very personal stuff with them, in fact it is a forum we all use to share personal stuff and family stuff that we cannot share on FB”. In most cases however, friends exchange private e-mail addresses and establish an ongoing e-mail conversation (Respondent E).

An important question is whether this private contact substitutes the contact on the public online communities and the contact with participants with whom one has no or superficial ties. Some participants feel that the contact with their close online friends has substituted their online participation. As one respondent indicates: “I think our small group of friends has for the most part substituted my activities on the online communities. Still, occasionally, I check in on the online communities to see if there is any new information

(Respondent E). For another respondent the contact on online communities is less substituted by private contact:

“I tend to talk to those who know my story more than new people, but if I see someone post a question or story that personally connects with mine I encourage and support them. I really spend my time with those I have been talking to the longest and those who have a personal story close to mine. It is not exclusive at all, I will befriend anyone who needs someone” (Respondent F).

The comments by both Respondent E and Respondent F indicate that participants (have to) make decisions about their time investments in the online community. Both respondents spent most of their time with online friends or at least with participants that know their story. Close ties may therefore be indicative of a substantial time investment by participants.

Every now and then participants still check-up with the online community because they are searching for new information. This search for new and up-to-date information was already discussed in the beginning of this chapter in relation to the motivations for online participation. The comment by Respondent E indicates that even when participants have made friends online, information can still be a motivation for online participation. When participants are active on the online community, they interact with acquaintances (superficial ties) and new participants (no ties). However, this contact is much less frequent than the contact with friends (close ties). This may be partly due to the relocation of online interaction from public communities to private messages, as was discussed earlier.

It can be concluded that the contact between members with close ties seems to have an effect on the online participation. The substitution of contact between the different type of ties, may have therefore also have an effect on the type of resources available to participants. This will be further explored in the next chapter.

## **7. Discussion**

In this chapter the most important results of this thesis will be compared with the results from other research. These results will be placed within a social capital framework to outline the most important findings from this research. Also the patterns and relationships between different results will be addressed. Finally the strengths and weaknesses of this thesis will be discussed.

### **7.1 Motives and goals**

It was previously argued that a consistency underlying the work of many authors in social capital theory is the conceptualisation of social capital as: “investments in social relations with expected returns” (Lin 2001:19). By addressing the goals and motivations for online participation, the returns that participants expect for their online participation were assessed.

Many participants expected to find more, other and new information online. Some participants were hoping to find information online because they were not receiving enough information from physicians, neurologists and headache specialists. Other participants were looking for information online to be more informed before going into a doctor’s visit. Both reasons can be seen as a way of patients to counter the historically asymmetrical doctor-patient relationship and become more empowered and in charge of their disease (Jacobson 2007:1-3).

Nevertheless, previous research indicates that the realisation of informed and empowered patients can be strained by patients that are reluctant to discuss information found online during a doctor’s visit (Henwood et al. 2003; Jacobson 2007; Kivits 2006). Kivits (2006:279) found that while patients may be active information seekers at home, in the doctor’s office they often return to their passive role of information seeker. The findings in this thesis however suggest that while some participants are merely looking for information online to become more informed, some participants are looking for information to use during a doctor’s visit. These participants may therefore not only become personally empowered, but may also translate this into self-efficacy in their interaction with their doctors. Although their doctors might respond negatively some participants are so dissatisfied with the inadequacy of information and care that they feel the need to take initiative and become more in charge of their disease.

The difference with Kivits’ (2006) study might be due to the nature of migraine disease: a chronic condition that lacks uniform and effective treatment. While this research was aimed at migraine, Kivits did not select respondents based on a specific condition but based on their activity on a particular website. Moreover Kivits (2006:271) aimed her search at websites that were concerned with healthy eating and overall fitness. In her research a third of participants considered themselves healthy. This research however only included

participants that did not consider themselves healthy and were actual patients. The degree of disability associated with migraines in combination with receiving inadequate care and no prospect of recovery could be a motivation for participants in this research to address the information found online in the doctor's office. However, to make more general and causal claims about migraine patients and their activities in the doctor's office, more research will be needed that specifically addresses this topic.

Another motivation for participation online was the expectation to find social interaction and support online. For many participants migraine attacks keep them close to their home, unable to participate in social gatherings. This means they are unable to attend traditional face-to-face support groups (Stronks 2003:20). Online groups can overcome this problem because participants can get support without leaving their home (Weinberg et al. 1995). Moreover, online communities are better able to generate a group of participants with great similarities and shared experiences than would be possible in an offline environment. The specialised nature of online communities allows interaction and bonding between participants with a similar background, interest or experience (Wright 2000:56). This creates an opportunity for the production and continuation of social capital since a high degree of interaction is established, which is the driving force behind the creation of social capital. This means that online communities create a unique opportunity for participants to draw upon interaction and support resources.

## **7.2 Investment**

The time invested in the online participation differed across participants. The highest degree of participation came from a participant that was administrator of her own community and blog. She used migraine sufferers and migraine.com to assemble participants for her community and blog for chronic migraineurs. This is supported by Butler et al. (2007:171) who found that individuals with a formal leadership role spend a substantial amount of time trying to build and sustain a community. These individuals are dedicating more time and effort in the online community than regular participants.

Nevertheless, other participants also spend time and effort on community building activities. The biggest difference is the way they contribute due to the different motivations for participation. Participants that are triggered by the information available on the online communities are less likely to invest much time in the community (Butler et al. 2007). Most of these participants are merely looking for information and are not looking to become part of a community. Participants that are hoping to find social interaction and support online are more likely to invest a substantial amount of time. These participants are the driving force behind community building activities (Butler et al. 2007).

Although the time invested in the community can be an indicator for community involvement, the findings in this research suggest that even small expressions of involvement and 'visibility' can contribute to the sustainability of online communities. Members support each other by little gestures and messages or even a simple 'like'. This means that time can be an indicator for active participation, but that community involvement must also be based on the activities during online participation.

An example of a community building activity is the sharing of personal migraine stories. This sharing of personal clinical information was also mentioned by Greene et al. (2010) as a frequently observed online activity. By sharing their story participants were looking for understanding and connectedness. As previously argued, visibility played an important part in feelings of understanding and connectedness. This because participants need some kind of acknowledgement or interaction to experience the community and individuals attached to that. This was supported by the considerations participants expressed about FB being the only place that is currently active. Interaction is thus essential because it is the driving force behind the production and continuation of social capital. Without this collective interaction social capital is not generated and individuals cannot benefit from it (Ferragina 2010). Active participation through content production and consumption is thus essential in sustaining online communities and achieving the beneficial characteristics such as social capital (Butler et al. 2007).

### **7.3 Resources**

Participants recognised different resources that they could draw upon. A first category emphasised by participants are the information resources. These information resources are also emphasised by different authors. Pénard & Poussing (2010:572) for instance mention valuable information in relation to resources. Ellison et al. (2007) discuss useful and non-redundant information in their article on FB use among college students. In addition Lin (2008:20) argues that the added value of social capital can be achieved through the facilitation of information channels. These channels can provide participants with useful information that would otherwise be unavailable.

Migraine.com provided an infrastructure that facilitated these information channels with otherwise unavailable information. The website features different perspectives from doctors, patient advocates, legal experts and caregivers. This creates a mixture of up-to-date and trustworthy medical information that is understandable, easy to use and practical. More importantly, this mixture of information cannot easily be found elsewhere which makes this website a 'one stop place' for many participants. Migraine.com thus provides a platform of information resources that enables participants to become more in charge of their disease and take up the ascribed role of active patients.

Another type of information that is not easily accessible on the Internet in general is experiential information. The experiential information differed from the straightforward medical information but was highly valued by participants. This is supported by Kivits (2004) who argues that patients are looking for the contextualisation of medical knowledge as well as experiential knowledge that goes beyond pure medical knowledge. The multiplicity of the information resources available on the communities allows for the personalisation of health information. Participants are able to draw upon different types of information resources relevant to their particular health problem, resulting in a more complete image of their health problem (Kivits 2006:279). The personalisation of health information is of particular importance for migraine patients since this is an integral part of the individual approach needed to establish appropriate treatment (Blau & MacGregor 1995; Lipton et al. 2000; Saper 1997:1; Winter et al. 2011:148)

Although these different types of information resources are available on the two communities, research suggests that the empowering nature of the Internet can be mitigated by patients' inability to comprehend and appraise information found online (Henwood et al. 2003; Jacobson 2007; Kivits 2006). This is supported by the concerns participants expressed regarding the credibility of information found online and the fact that they valued the authority and information assimilation of migraine.com. A website like migraine.com can thus reduce barriers substantially because it assimilates trustworthy information checked by medical professionals. The information on migraine.com is already assessed and appraised by medical professionals so that participants can rely on this information to be credible. Moreover, the different and non-medical perspectives provide a context in which the information is received and understood.

Another category of resources recognised by participants were the interaction resources that consist of getting advice and feedback. Greene et al. (2010) and Ferlander (2007) also mention the disease specific guidance and feedback. The support resources are also frequently referred to in the literature. DiMaggio et al. (2001) and Greene et al. (2010) for instance mention social and interpersonal support as online activities. Drentea & Moren-Cross (2005) and Ferlander (2007) on the other hand emphasise emotional support. Drentea & Moren-Cross (2005:929-931) examine emotional support on online mother communities and argue that participants use their online ties to vent frustrations, bolster self-esteem and seek empathy. Ferlander (2007) also argues that emotional support includes feelings of empathy, caring and trust. Although participants emphasised that empathy is important and that friends and family are sympathetic, participants attach more value to receiving support through the understanding from fellow patients. For participants empathy and understanding differ because feelings of empathy come from family and friends that are never able to fully grasp the experience of having a migraine.

Understanding is thus extremely important for participants and comes from shared experiences. These shared experiences are also important in the process of validation. Many participants value the opportunity offered by these communities to have other patients validate their symptoms and issues. This validation makes participants feel normal because others have similar experiences. Lin (2001:20) referred to this mechanism of social capital as the reinforcement of individual identity. By the understanding and validation of symptoms and other issues participants may feel recognised as a worthy group member. According to Lin (2001:20) being recognised as a worthy group member provides support that is essential for the mental health of participants and their entitlement to resources. Poder (2010:4) also argues that the support that comes from understanding and validation can facilitate mental health by countering feelings of vulnerability, insecurity and abandonment.

#### **7.4 Community ties**

The community ties observed on migraine sufferers and migraine.com were characterised as: no ties, superficial and/or strong ties. This categorisation shows a parallel with Granovetter's theory of tie strength (1973). No ties equal Granovetter's absent ties, indicating that there is no interaction or sense of recognition between participants. Superficial ties are similar to Granovetter's weak ties. These weak ties refer to acquaintances and the superficial ties in this research also refer to acquaintances with a sense of recognition. The close ties equal Granovetter's strong ties and refer to friendships. According to Granovetter (1973:1361) this categorisation is based on tie strength that is determined by: time, emotional intensity, intimacy and reciprocal services. Some of these factors that determine tie strength can also be observed in this research.

The degree of intimacy can for instance be determined by the range of topics that are discussed by participants. No ties mean no interaction and no topics that are discussed. This means that tie strength is low. Participants with superficial ties mainly discussed medical issues without too much personal information. Participants with close ties on the other hand discussed a wide range of topics that included very private information. In order to establish these close ties and to be able to discuss a wide range of topics, participants invested a substantial amount of time into these relationships. The amount of time invested in the ties can therefore be indicative of tie strength, as was also argued by Granovetter (1973:1361). This indicates that superficial ties have bigger tie strength than no ties, but smaller tie strength than close ties due to the range of topics that is discussed and the amount of time that is invested in the relationships.

Besides the tie strength categorisation Granovetter argues that "ideas, information and influences that are socially distant" from an individual are more likely to diffuse through weak ties (Granovetter 1973:1370-1372). This means that participants with superficial ties

are most likely to find information online that would otherwise be unavailable to them. Participants with close ties who relocate their interaction to private messages and are restricted to a small group of online friends, reduce the likelihood to find valuable and otherwise unavailable information. This could mean that when participants make friends online the focus of resource types can shift from information to interaction and support resources. This is because participants with strong ties emphasise the support system instead of the informational function. Of course these analogies need to be treated with caution and need thorough research in the future.

Finally participants referred to the geographical spread between online friends. Many participants were eager to meet their online friends with whom they have strong ties. This is supported by other research suggesting that the friendships made online can migrate to other and even face-to-face settings (Hampton & Wellmann 2002; Mesch & Talmut 2006; Parks & Floyd 1996; Ross et al. 2009). The migration to other settings also relates to the previously mentioned relocation of public to private messages and forums observed in close ties.

### **7.5 Strengths and weaknesses of this research**

This thesis aimed to address social capital in online migraine communities by studying two online migraine communities. Because both communities were on FB but only migraine.com has a website with different applications, the cases were considered to vary at only one variable. Three methods were used to fully describe the characteristics of the two cases while incorporating the interpretations of participants. This method triangulation can be seen as a strength of this thesis. The observations online can also be seen as a strong point because no interventions in the dynamics of the communities were needed. This resulted in undisrupted pictures of the practice on both online communities.

The interviews complemented the observations and enabled deeper analysis of the motivations and experiences of participants. A downside of the e-interview is the lack of body language and facial expressions that can be observed during face-to-face interviews (Bampton & Cowton 2002). Although the lack of this information can result in misunderstanding or lower data quality, the effects are potentially moderated because interview answers were compared with the observations. Moreover the e-interviews included regular episodes of questions and answers that allowed statements and conclusions to be checked with respondents. Finally the e-interview created a research opportunity that could not have been established based on face-to-face interviews due to geographical spread (Bampton & Cowton 2002).

The selection of respondents could potentially be seen as a weakness of the study. Respondents were selected based on their membership in one of the two communities and



their willingness to participate. Theoretically this could mean that the respondents were not representative for the entire community (in both cases) as all respondents were female. But since most participants on online communities are female and the percentage of migraine patients is substantially higher in women, this was not considered a big limitation. In addition, there was a great variety in respondents regarding age, level of online activity, membership in other communities, period of participation on a community and the motivations for participation that could have reduced the likelihood of a biased sample.

The amount of respondents could also be seen as a limitation of this research. The amount of respondents that were interviewed differed between the two cases and was based on availability. Maybe a longer period of data collection could have increased the amount of respondents. Nevertheless, several research calls were placed on both communities and too many attempts to recruit respondents could be counterproductive.

Another weakness of the study could be the specificity of the two cases. This could limit the extent to which the findings from this research can be generalised to non-FB communities or online communities aimed at different health issues. Nevertheless, general conclusions can be provided regarding the difference between a FB community attached to a website and a FB community that stands by itself.

## 8. Conclusion

This thesis aimed to gain insight in how migraine communities on FB facilitate interaction and provide patients with certain resources that would otherwise be unavailable to them. Special attention was devoted to the role of community ties in this process. Through document analysis, observations and interviews two cases were analysed: the website and FB community of migraine.com and the FB community of migraine sufferers.

The findings discussed in this thesis suggest that online community ties differ in their strength and availability of resources. The difference across community ties is associated with the motivation for online participation and the expected results from this participation. Participants with no community ties had no interest in becoming part of a community because they were only looking for information related to their migraines. Therefore they did not support or interact with community members and did not qualify as active participants. Because both migraine.com and migraine sufferers are communities that are publicly available, the information shared by active participants was also available to these non-active participants. Participants with no community ties were using the information resources to find up-to-date, medical and experiential information that could help them understand and cope with their illness.

Participants with superficial community ties have access to all three types of resources that were recognised by participants in this research. Through their investments in the community – small gestures, comments or ‘likes’ – these participants establish a sense of recognition with other members of the community. This allows them to interact, get support and access information. This comes from a motivation to find information, interact and get support from the online communities.

Participants with close community ties also have access to all three types of resources. Nevertheless for these participants information resources were of less importance than the interaction and support resources. Besides the fact that participants with close ties emphasised the interaction and support resources more than the information resources, there was less diversity in the information resources for these participants. This is because the close community ties are limited to a small group of friends and communication is often relocated to private messages. This results in communication that is restricted to a small group of friends that often share similar characteristics. This prohibits the diffusion of socially distant information that is associated with weaker ties on online communities.

It can be concluded that the community ties are essential in gaining access to particular resources. This because not all types of community ties have access to all types of resources. This stresses the importance of interaction among participants since interaction is

necessary to establish community ties. Interaction is therefore also the driving force behind the production and continuation of social capital.

Social capital in this research is a mechanism to access certain resources and requires individual and collective action. For participants to exploit the full range of resources, not only individual action but also collective action is required. Individuals need to invest time and effort into interaction in order to gain access to particular resources. But without collective action there will be no resources that individuals can draw upon. This relates to the dynamic view of social capital that incorporates an individual and aggregate component. But in order to truly make claims on a meso and macro level further research would be needed. Because of the lack of research that combined FB communities, social capital theory and patient empowerment this research focussed on individuals in order to explore and assess the meanings of online communities and the potential benefits. It would therefore be interesting to see what these communities can mean in relation to social capital and patient empowerment when a community view is applied. Nevertheless it will be challenging to find appropriate measures that can combine all three levels of return.

Nonetheless this research indicates that FB communities can be an interesting research site given that FB is increasingly becoming part of social life. Although research that focuses on FB communities is growing, more research is needed to assess the possibilities and consequences of health-related communities on FB. This thesis already showed that FB communities can provide a platform and infrastructure with endless opportunities for patient education, empowerment, interaction and support. But to overcome some barriers associated with credibility and privacy, FB communities can benefit from the availability of a website like migraine.com. Because information is reviewed by individuals and organisations with authority, the information and community attached to the website acquire credibility. Moreover the issue-specific assimilation of information is user-friendly and the tools and interesting perspectives are highly valued by participants. Bringing together information, interaction and support gives patients the opportunity to actually take up the role they are often assigned to. The only thing migraine.com could change in order to sustain and further develop their community would be to introduce private environments within the website and/or community since participants may see this as a barrier or because participants may relocate to private environments.

## References

Adams, S.A. 2010. 'Blog-based applications and health information: Two case studies that illustrate important questions for Consumer Health Informatics (CHI) research'. *International Journal of Medical Informatics* 79(6):89-96.

Adams, S.A. 2011. 'Sourcing the crowd for health services improvement: The reflective patient and "share-your-experience" websites.' *Social Science & Medicine* 72:1069-1076.

Adams, S.A. & A. de Bont. 2007. 'Information Rx: Prescribing Good Consumerism and Responsible Citizenship.' *Health Care Analysis* 15:273:290.

Agneessens, F. 2006. *Different theories and measures of social capital: Applications in a knowledge-intensive work environment*. Ghent: Ghent University.

Andlin-Sobocki, P. et al. 2005. 'Costs of disorders of the brain in Europe.' *European Journal of Neurology* 12:S1-S27.

(Apple). 2011. IPhone Health-Apps: Healthy Heart Journal [Internet]. Apple, 27-10-2011 [cited on 27-10-2011]. Reached at <http://www.iphonehealthapps.net/2009/11/05/Healthy-Heart-Journal/>

Barbot, J. 2006. 'How to build an "active" patient? The work of AIDS associations in France.' *Social Science & Medicine* 62(3):538-551.

Bampton, R. & C. J. Cowton. 2002. 'The e-interview.' *FQS Forum: Qualitative Social Research* 3(2):1-12.

Bankston, C. L. & M. Zhou 2002. 'Social Capital as a Process: The Meanings and Problems of a Theoretical Metaphor.' *Social Inquiry* 72(2):285-317.

Baum, F. 2000. 'Social capital, economic capital and power: further issues for a public health agenda.' *Journal of Epidemiology and Community Health* 54(6):409-410.

Baum, F.E. & C. Palmer. 2002. 'Opportunity structures: urban landscape, social capital and health promotion in Australia.' *Health Promotion International* 17(4):351-361.

- Baum, F.E. & A.M. Ziersch. 2003. 'Social capital.' *Journal of Epidemiology & Community Health* 57(5):320-323.
- Bell, C. & H. Newby. 1974. 'Introduction.' In: C. Bell & H. Newby (Eds.), *Sociology of Community: A Selection of Readings*, xliii-lii. Abingdon: Frank Cass and Company Limited.
- Berg, J. & L.J. Stovner. 2005. 'Cost of migraine and other headaches in Europe.' *European Journal of Neurology* 12(1):59-62.
- Blau, J.N. & E. A. MacGregor. 1995. 'Migraine consultations: a triangle of viewpoints.' *Headache* 35(2):104-106.
- Bourdieu, P. 1973. 'Cultural reproduction and social reproduction.' In: Brown, R. (Ed.), *Knowledge, Education and Cultural Change: Papers in the Sociology of Education*, 71-112. London: Tavistock Publications.
- Bourdieu, P. 1997. 'The Forms of Capital.' In: A. Halsey, H. Lauder, P. Brown & A. Stuart Wells (Eds.), *Education: Culture, Economy and Society*, 46-58. Oxford: Oxford University Press.
- Bourdieu, P. & J.C. Passeron 1977. *Reproduction in Education, Society and Culture*. London: Sage Publications.
- Bowen, G. A. 2009. 'Document Analysis as a Qualitative Research Method.' *Qualitative Research Journal* 9(2):27-40.
- Brewer, G. A. 2003. 'Building Social Capital: Civic Attitude and Behavior of Public Servants.' *Journal of Public Administration Research and Theory* 13(1):5-26.
- Bruhn, J.G. 2005. *The Sociology of Community Connections*. New York: Springer.
- Butler, B. et al. 2007. 'Community Effort in Online Communities: Who does the work and Why?' In S. Weisband (Ed.), *Leadership at a Distance: Research in Technologically-Supported Work*, 171-194. New York: Lawrence Erlbaum Associates.
- Buys, L. & V. Bow 2002. *The impact of privacy on Social Capital*. Brisbane: Queensland University of Technology.

- Carlson, P. 2004. 'The European health divide: a matter of financial or social capital?' *Social Science & Medicine* 59(9):1985-1992.
- Carr-Hill, R. et al. 1998. 'Do minutes count? Consultation lengths in general practice.' *Journal of Health Services Research & Policy* 3(4):207-213.
- Cavanagh, A. 2007. 'Community.' In A. Cavanagh (Ed.), *Sociology in the Age of the Internet*, 102-119. Maidenhead: Open University Press.
- Claridge, T. 2012. *Levels at Which Social Capital is Located*. [Internet]. Social Capital Research, [cited at 01-06-2012]. Reached at <http://www.socialcapitalresearch.com/levels.html>
- Coleman, J. S. 1988. 'Social Capital in the Creation of Human Capital.' *American Journal of Sociology* 94(S):95-120.
- Compaine, B.M. 2001. *The digital divide: facing a crisis or creating a myth?* Cambridge: The MIT Press.
- Davies, A. 2001. *But we knew that already! – A study into the relationship between social capital and volunteering*. Sheffield: Home Start.
- Delanty, G. 2010. 'Introduction.' In G. Delanty (Ed.), *Community*, x-xvi. Abingdon: Routledge. [2003].
- DiMaggio, P. et al. 2001. 'Social Implications of the Internet.' *Annual Review of Sociology* 27:307:336.
- Dowson, A. & S. Jagger. 1999. 'The UK patient survey: quality of life treatment.' *Current Medical Research & Opinion* 15(4):241-253.
- Drentea, P. & L. Moren-Cross. 2005. 'Social capital and social support on the web: the case of an internet mother site.' *Sociology of Health & Illness* 27(7):920:943.
- Eaton, L. 2002. 'A third of Europeans and almost half of Americans use Internet for health information.' *British Medical Journal* 325(7371):989.

Ellison, N.B. et al. 2007. 'The Benefits of Facebook "Friends": Social Capital and College Students' Use of Online Social Network Sites.' *Journal of Computer-Mediated Communication* 12(4):1143:1168.

Eysenbach, G. 2000. 'Consumer health informatics.' *British Medical Journal*. 320:1713-1716.

(Facebook). 2012a. *Diabetes* [Internet]. Facebook, 04-06-2012 [cited on 04-06-2012]. Reached at <http://www.facebook.com/#!/Diabetes.n.Diabetics>

(Facebook). 2012b. *Statistics* [Internet]. Facebook, 04-06-2012 [cited on 04-06-2012]. Reached at [http://www.facebook.com/facebook?sk=app\\_10531514314#!/press/info.php?statistics](http://www.facebook.com/facebook?sk=app_10531514314#!/press/info.php?statistics)

(Facebook). 2012c. *Algemene gegevens* [Internet]. Facebook, 04-06-2012 [cited on 04-06-2012]. Reached at <http://www.facebook.com/#!/facebook?sk=info>

(Facebook). 2012d. *Info* [Internet]. Facebook, 04-06-2012 [cited on 04-06-2012]. Reached at <http://www.facebook.com/#!/MigraineDotCom/info>

(Facebook). 2012e. *Over de groep* [Internet]. Facebook, 12-06-2012 [cited on 12-06-2012]. Reached at <http://www.facebook.com/#!/groups/2260202014/members/>

Falk, I. & S. Kilpatrick 2000. 'What is social capital? A study of interaction in a rural community.' *Sociologica Ruralis* 40(1):87-110.

Ferguson, T. 1997. 'Health online and the empowered medical consumer.' *Journal of Quality Improvement* 23(5):251-257.

Ferlander, S. 2007. 'The Importance of Different Forms of Social Capital for Health.' *Acta Sociologica* 50(2):115-128.

Ferragina, E. 2010. 'Social Capital and Equality: Tocqueville's Legacy: Rethinking social capital in relation with income inequalities.' *Tocqueville Review* XXXI(1):73-98.

Flick, U. 2009. *An Introduction to Qualitative Research*. London: Sage. [1998]

- Fuchs, C. 2010a. 'Labour in Informational Capitalism and on the Internet.' *The Information Society* 26(3):179-196.
- Fuchs, C. 2010b. 'Class, knowledge and new media.' *Media, Culture & Society* 32(1):141-150.
- Fuchs, C. 2011. 'Web 2.0, Prosumption, and Surveillance.' *Surveillance & Society* 8(3):288-309.
- Gallagher, R. M. 2004. 'What do patients want from acute migraine treatment?' *Cephalgia* 24(2):8-15.
- Gillham, B. 2000. 'Case Study Research: The Qualitative Dimension.' In: B. Gillham (Ed.), *Case study research methods*, 9-14. London: Continuum.
- Goadsby, P. J. et al. 2002. 'Migraine – current understanding and treatment.' *The New England Journal of Medicine* 346(4):257-270.
- Glaeser, E. L. et al. 2002. 'An economic approach to social capital.' *Economic Journal* 112(483):F437-F458.
- Granovetter, M.S. 1973. 'The Strength of Weak Ties.' *American Journal of Sociology* 78(6):1360-1380.
- Gray, J.A. M. 2002. *The resourceful patient*. Oxford: eRosetta Press.
- Greene, J.A. et al. 2010. 'Online Social Networking by Patients with Diabetes: A Qualitative Evaluation of Communication with Facebook.' *Journal of General Internal Medicine* 26(3):287:292.
- Hackworth, B.A. & M.B. Kunz. 2011. 'Health Care and Social Media: Building Relationships via Social Networks.' *Academy of Health Care Management Journal* 7(2):1-15.
- Halpern, D. 2005. *Social Capital*. Cambridge: Polity Press. [2005]
- Hampton, K. & B. Wellmann. 2002. 'The not so global village of Netville.' In: B. Wellmann & C. Haythornthwaite (Eds.), *The Internet in everyday life*, 345-372. Oxford: Blackwell.



Hawe, P. & A. Shiell. 2000. 'Social Capital and Health Promotion: A Review.' *Social Science and Medicine* 32:148-155.

Hawn, C. 2009. 'Take Two Aspirin And Tweet Me In The Morning: How Twitter, Facebook, And Other Social Media Are Reshaping Health Care.' *Health Affairs* 28(2):361-368.

Health Union. 2012. Migraine.com [Internet]. Health Union, 06-06-2012 [cited on 06-06-2012]. Available on <http://migraine.com/>

Henwood, F. et al. 2003. "Ignorance is Bliss Sometimes": constraints on the emergence of the "informed patient" in the changing landscape of health information.' *Sociology of Health and Illness* 25(6):589-607.

Hoang, H. & B. Antoncic. 2003. 'Network-based research in entrepreneurship: A critical review.' *Journal of Business Venturing* 18(2):165-187.

Idriss, S. Z. et al. 2009. 'The role of online support communities: benefits of expanded social networks to patients with psoriasis.' *Archives of Dermatology* 145(1):46-51.

Jack, S. 2005. 'The role, use and activation of strong and weak network ties: A qualitative analysis.' *Journal of Management Studies* 42(6):1233-1259.

Jacobson, P. 2007. 'Empowering the physician-patient relationship: The effect of the Internet.' *Partnership: The Canadian Journal of Library and Information Practice and Research* 2(1):1-13.

Joffe, H. & L. Hardley. 2004. 'Content and thematic analysis.' In: D. F. Marks & L. Hardley (Eds.), *Research Methods for Clinical and Health Psychology*, 56-68. London: Sage.

Kivits, J. 2004. 'Researching the "Informed Patient": The case of online health information seekers.' *Information, Communication & Society* 7(4):510-530.

Kivits, J. 2006. 'Informed Patients and the Internet: A Mediated Context for Consultations with Health Professionals.' *Journal of Health Psychology* 11(2):269-282.

Koster, W. de. 2010. *Nowhere I Could Talk Like That: Togetherness and identity on online forums*. Rotterdam: Erasmus University.

Kraut, R. et al. 1998. 'Internet paradox: A social technology that reduces social involvement and psychological well-being?'. *American Journal of Psychology* 53(9):1011-1031.

Kryst, S. & E. Scherl. 1994. 'A population-based survey on the social and personal impact of Headache.' *Headache* 34(6):344-350.

Lemire, M. 2010. 'What can be expected of information and communication technologies in terms of patient empowerment in health?'. *Journal of Health Organization and Management* 24(2):167-181.

Leonardi, M. et al. 2005. 'The global burden of migraine: measuring disability in headache disorders with WHO's Classification of Functioning, Disability and Health (ICF).' *Journal of Headache & Pain* 6(6):429-440.

Leonardi, M. et al. 2010. 'Functioning and disability in migraine'. *Disability and Rehabilitation* 32(S1):S23-S32.

Lewiss, J. & J. Ritchie. 2003 'Generalising from Qualitative Research.' In: J. Lewiss & J. Ritchie (Eds.), *Qualitative Research Practice: A Guide for Social Science Students and Researchers*, 264-286.

Lin, N. 1982. 'Social Resources and Instrumental Action.' In: P.V. Marsden & N. Lin (Eds.), *Social Structure and Network Analysis*, 131-145. Beverly Hills: Sage.

Lin, N. 1999. 'Building a Network Theory of Social Capital.' *Connections* 22(1):28-51.

Lin, N. 2001. *Social Capital: A Theory of Social Structure and Action*. Cambridge: Cambridge University Press.

Lin, N. 2008. 'A Network Theory of Social Capital.' In: D. Castiglione, J.W. van Deth & G. Wolleb (Eds.), *The Handbook of Social Capital*, 50-69. New York: Oxford University Press.

Lipton, R. B. et al. 2000. 'Migraine: diagnosis and assessment of disability.' *Review of Contemporary Pharmacotherapy* 11:63-67.

Lipton, R. B. et al. 2001. 'Migraine Diagnosis and Treatment: Results from the American Migraine Study II.' *Headache* 41(7):638-645.

LUMC. 2012. Informatie over migraine [Internet]. Leids Universitair Medisch Centrum, 10-01-2011 [cited on 18-11-2011]. Reached at <http://www.lumc.nl/con/5035/107910/107927/>

Lynch, J. et al. 2000. 'Social capital – Is it a good investment strategy for public health?' *Journal of Epidemiology and Community Health* 54(6):404-408.

Malina, A. 1999. 'Perspectives on citizen democratisation and alienation in the virtual public sphere.' In: B.N. Hague & B.D. Loader (Eds.), *Digital democracy: discourse and decision making in the Information Age*, 23-38. London: Routledge.

Mann, C. & F. Stewart. 2000. *Internet Communication and Qualitative Research: A Handbook for Researching Online*. London: Sage.

Manzerolle, V. 'Mobilizing the audience commodity: Digital labour in a wireless world.' *Ephemera: theory & politics in organization* 10(3/4):455-469.

Markham, A.N. 2004. 'Internet communication as a tool for qualitative research.' In: D. Silverman (Ed.), *Qualitative Research: Theory, Method and Practice*, 95-124. London: Sage.

Marx, K. 1849. *Wage-labour and Capital*. New York: International Publishers.

Marx, K. 1867. *Capital Volume 1*. London: Penguin Books.

Menken, M. et al. 2000. 'The global burden of disease study: implications for neurology.' *Archives of Neurology* 57(3):418-420.

Mesch, G. & I. Talmud. 2006. 'The Quality of Online and Offline Relationships: The Role of Multiplexity and Duration of Social Relationships.' *The Information Society* 22(3):137-148.

Miyata, K. 2002. 'Social support for Japanese mothers online and offline.' In: B. Wellman & C. Haythornthwaite (Eds.), *The Internet in Everyday Life*, 520-548. Malden: Blackwell Publishers.

Mort, M. et al. 2009. 'Making and Unmaking Telepatients: Identity and Governance in New Health Technologies.' *Science, Technology & Human Values* 34(1):9-33.

- Muntaner, C. et al. 2000. 'Social capital and the third way in public health.' *Critical Public Health* 10(2):107-121.
- Narayan, D. & L. Pritchett. 1999. 'Cents and sociability: household income and social capital in rural Tanzania.' *Economic Development and Social Change* 47(4):871-897.
- Nie, N. et al. 2002. 'Internet use, interpersonal relations, and sociability.' In: B. Wellman & C.A. Haythornthwaite (Eds.), *The Internet in Everyday Life*, 215-243. Malden: Blackwell Publishers.
- Norris, P. 1996. 'Does Television Erode Social Capital? A Reply to Putnam.' *Political Science and Politics* 29(3):474-480.
- Norris, P. 2001. *Digital Divide: Civic Engagement, Information Poverty, and the Internet Worldwide*. Cambridge: Cambridge University Press.
- Parent, I. & N. Cruickshank. 2009. 'The Growth of the Internet and Knowledge Networks, and their Impact in the Developing World.' *Information Development* 25(2):91-98.
- Parks, M. R. & R. Floyd. 1996. 'Making friends in cyberspace.' *Journal of Communication* 46:80-97.
- Pénard, T. & N. Poussing. 2010. 'Internet Use and Social Capital: The Strength of Weak Ties.' *Journal of Economic Issues* XLIV(3):569-595.
- Poder, T.G. 2010. 'Social Capital and Health: What the Empirical Literature Teaches Us?' *Global Journal of Health Science* 2(1):3-6.
- Portes, A. 1998. 'Social Capital: Its Origins and Applications in Modern Sociology.' *Annual Review of Sociology* 24:1-24.
- Portes, A. 2000. 'The Two Meanings of Social Capital.' *Sociological Forum* 15(1):1-12.
- Preece, J. 2000. *Online Communities: Designing Usability and Supporting Sociability*. New York: John Wiley & Sons.
- Preece, J. 2001. 'Sociability and usability in online communities: Determining and measuring success.' *Behaviour & Information Technology* 20(5):347-356.

Preece, J. & D. Maloney-Krichmar. 2003. 'Online Communities.' In: J.A. Jacko & A. Sears (Eds.), *Handbook of Human-Computer Interaction: Fundamentals, Evolving Technologies and Emerging Applications*, 596-620. Mahwah: Lawrence Erlbaum Associates Inc. Publishers.

Putnam, R. D. 1993. *Making Democracy Work: Civic Traditions in Modern Italy*. Princeton: Princeton University Press.

Putnam, R. D. 1995. 'Bowling alone: the strange disappearance of civic America.' *Journal of Democracy* 6(1):65-78.

Putnam, R.D. 1996. 'The Strange Disappearance of Civic America.' *American Prospect* 7(24):1-18.

Quan-Haase, A. & B. Wellman. 2004. 'How Does the Internet Affect Social Capital?' In: M. Huysman & V. Wulf (Eds.), *Social Capital and Information Technology*, 113-132. Cambridge: The MIT Press.

Rheingold, H. 1993. *The Virtual Community: Homesteading on the Electronic Frontier*. Boston: Addison-Wesley Publishing Company.

Ritzer, G. & N. Jurgenson. 2010. 'Production, Consumption, Prosumption: 'The nature of capitalism in the age of the digital 'prosumer'.' *Journal of Consumer Culture* 10(1):13-36.

Ross, C. et al. 2009. 'Personality and motivations associated with Facebook use.' *Computers in Human Behaviour* 25(1):578-586.

Sampson, R.J. et al. 1999. 'Beyond Social Capital: Spatial Dynamics of Collective Efficacy for Children.' *American Sociological Review* 64(5):633-660.

Sander, T. H. 2002. 'Social Capital and New Urbanism: Leading a Civic Horse to Water?' *National Civic Review* 91(3):213-234.

Santanello, N.C. et al. 1995. 'Validation of a new quality of life questionnaire for acute migraine headache.' *Headache* 35(6):330-337.

Saper, J. R. 1997 'Diagnosis and symptomatic treatment of migraine.' *Headache* 37(1):1-14.

Schuller, T. et al. 2000. 'Social Capital: A Review and Critique.' In: T. Schuller, S. Baron & J. Field (Eds.), *Social capital: critical perspectives*, 1-38. Oxford: Oxford University Press.

Seale, C. 2003. 'Health and media: an overview.' *Sociology of Health & Illness* 25(6):513-531.

Seawright, J. & J. Gerring 2008. 'Case Selection Techniques in Case Study Research: A Menu of Qualitative and Quantitative Options.' *Political Research Quarterly* 61(2):294-308.

Selwyn, N. 2004. 'Reconsidering Political and Popular Understandings of the Digital Divide.' *New Media Society* 6(3):341-362.

Silberstein, S. D. 2000. 'Practice parameter: evidence-based guidelines for migraine headache (an evidence-based review).' *Neurology* 55(6):754-762.

Siisiäinen, M. 2000. *Two Concepts of Social Capital: Bourdieu vs. Putnam*. Jyväskylä: University of Jyväskylä.

Souza, C.S. de. & Preece, J. 2004. 'A framework for analysing and understanding online communities.' *Interacting with Computers* 16(1):579-610.

Stake, R. E. 1995. 'The unique case.' In: R. E. Stake (Ed.), *The art of case study research*, 1-14. Thousand Oaks: Sage.

Stovner, L. J. & L. P. Quieroz. 2011. 'The Burden of Headache.' In: P. Martelletti & T. J. Steiner (Eds.), *Handbook of Headache: Practical Management*, 37-44. London: Springer.

Stronks, D.L. 2003. 'Stress and Daily Functioning in Migraine.' Rotterdam: Erasmus University.

Swanborn, P. 2010. 'What is a case study?' In: P. Swanborn (Ed.), *Case Study Research: What, Why and How?*, 1-23. London: Sage.

Toffler, A. 1980. *The Third Wave*. New York: William Morrow.

Wangberg, S.C. et al. 2008. 'Relations between Internet use, social-economic status (SES), social support and subjective health.' *Health Promotion International* 23(1):70-77.

Weber, M. 1911. 'Geschäftsbericht. In Verhandlungen des ersten deutschen Soziologentages vom 19.-22.' In: M. Weber (Ed.), *Schrift der Deutschen Gesellschaft Für Soziologie*, 39-61. Frankfurt am Main: Tübingen.

Weinberg, N. et al. 1995. 'Computer-mediated support groups.' *Social Work with Group* 17:43-54.

(WHO). 2004. Headache disorders [Internet]. World Health Organisation, 31-03-2004 [cited on 17-11-2011]. Reached at <http://www.who.int/mediacentre/factsheets/fs277/en/>

Wilbur, S.P. 1997. 'An Archaeology of Cyberspaces: Virtuality, Community, Identity.' In: D. Porter (Ed.), *Internet Culture*, 5-22. London: Routledge.

Willson, M.A. 2006. *Technically Together: Re-Thinking Community within Techno-Society*. New York: Peter Lang.

Winter, A.C. et al. 2011. 'Associations between lifestyle factors and headache.' *Journal of Headache & Pain* 12(4):147-155.

Woessmann, L. 2011. 'Surfing Alone? The Internet and Social Capital: Evidence from an Unforeseeable Technological Mistake.' *IZA Discussion Paper* No. 5747

Woolcock, M. 1998. 'Social Capital and Economic Development: Toward a Theoretical Synthesis and Policy Framework.' *Theory and Society* 27(2):151-208.

Woolcock, M. & D. Narayan. 2000. 'Social Capital: Implications for Development Theory, Research and Policy.' *The World Bank Research Observer* 15(2):225-249.

(Worldbank). 2012. Internet users [Internet]. Worldbank, 23-04-2012 [cited on 23-04-2012]. Reached at [http://databank.worldbank.org/ddp/html-jsp/QuickViewReport.jsp?RowAxis=WDI\\_Ctry~&ColAxis=WDI\\_Time~&PageAxis=WDI\\_Series~&PageAxisCaption=Series~&RowAxisCaption=Country~&ColAxisCaption=Time~&NEW\\_REPORT\\_SCALE=1&NEW\\_REPORT\\_PRECISION=0.0&newReport=yes&IS\\_REPORT\\_IN\\_REFRESH\\_MODE=true&IS\\_CODE\\_REQUIRED=0&COMMA\\_SEP=true](http://databank.worldbank.org/ddp/html-jsp/QuickViewReport.jsp?RowAxis=WDI_Ctry~&ColAxis=WDI_Time~&PageAxis=WDI_Series~&PageAxisCaption=Series~&RowAxisCaption=Country~&ColAxisCaption=Time~&NEW_REPORT_SCALE=1&NEW_REPORT_PRECISION=0.0&newReport=yes&IS_REPORT_IN_REFRESH_MODE=true&IS_CODE_REQUIRED=0&COMMA_SEP=true)

Wright, K. D. 2000. 'Perceptions of on-line support providers: An examination of perceived homophily, source credibility, communication and social support within on-line support groups.' *Communication Quarterly* 48:44-59.



# Appendix 1 – FB community migraine.com

facebook  Zoeken Jacqueline Vrienden zoeken Startpagina

**Migraine.com**  
28.464 personen vinden dit leuk · 903 praten hierover

Gezondheid/Gezondheid  
At Migraine.com we empower patients and caregivers to take control of migraine disease by providing a platform to learn, educate, and connect with peers and healthcare

Info Foto's Vind-ik-leuks Welcome Migraine News

Belangrijkste berichten

Bericht  
Schrijf iets...

Migraine.com heeft een link gedeeld.  
ongeveer een uur geleden

In honor of Migraine Awareness Month, give us your most personal, embarrassing or secret stories of living with migraine disease. Be as open as you dare! Read more about how to submit your blog: <http://migraine.com/?p=38607>  
Vertaling bekijken

Recente berichten van anderen over Migraine.com Alles weergeven

- Kerry Craig**  
I was just prescribed Depakote ER for my migraines. Wond...  
2 uur geleden
- Kasey Harris**  
The Portrayal of Migraine in Popular Music: Observations...  
1 · 3 uur geleden
- Len UninhibitedSpirit Springer**  
I have been a migraine sufferer since 9 years old and unfor...  
1 · 4 uur geleden
- Lisa Marechal Tober**  
Although not a migraineur myself, I am the primary care...  
2 · Gisteren om 19:02

Nu mei 2012 2011  
Is nu lid van Facebook

MEER ONLINE VRIENDEN (2)

Zoeken

facebook  Zoeken Jacqueline Vrienden zoeken Startpagina

**Migraine.com** Tijdslijn Nu Belangrijkste berichten Vind ik leuk

Vind ik leuk · Reageren · Delen  
14 personen vinden dit leuk.  
Bekijk alle 11 reacties

**Joanna Foster McElroy** I've been getting botox shots every three months in my forehead, around and above my ears/temple area, and the length of my shoulders (one side to the other). Although my migraines haven't completely gone away, the botox has DEFINITELY but...  
41 minuten geleden · Vind ik leuk

**Joanna Foster McElroy** as for the question above, migraines definitely interfere with life. I hate the "anOTHER one?" look I get from friends and family members. I've missed many family gatherings or time with friends, or I especially hate that there are many days I can't help with my kids, it's tough trying to explain to a 3 year old that although mommy looks OK, she really isn't.  
38 minuten geleden · Vind ik leuk

Schrijf een reactie...

Migraine.com heeft een link gedeeld.  
20 uur geleden

Breaking news: A new migraine gene discovery gives Migraineurs hope for future research leading to targeted diagnosis and treatment. Read more: <http://migraine.com/?p=38618>

**Migraine Genes: X Marks the Spot -- Migraine.com**  
migraine.com

<http://www.facebook.com/#>

The Migraine Awareness Month blog challenge for today is: Choose a theme song for Migraine disease or your headache disorder. Read more about Teri's selection: <http://migraine.com/blog/migraine-awareness-month-6-name-that-tune/>  
Vertaling bekijken

**Migraine Awareness Month #6: Name That Tune! -- Migraine.com**  
migraine.com

Migraine Awareness Month #6: Name That Tune! -- Migraine.com

Vind ik leuk · Reageren · Delen  
5 personen vinden dit leuk.  
Bekijk alle 11 reacties

**Kimberly Parrott Willingham** Twisted sister, we're not gonna take it!  
29 minuten geleden via mobiel · Vind ik leuk

**Lindsey Melnyk** WASTED LIFE by seether, b/c i feel like most of my life has been wasted b/c of the whole having migraines almost every day, so, find me a way, to leave this wasted life. maybe it'll be better in the next life for me?  
24 minuten geleden · Vind ik leuk · 1

Schrijf een reactie...

Migraine.com heeft een link gedeeld.  
22 uur geleden

Nu mei 2012 2011  
Is nu lid van Facebook

Gesponsord  
**Vrouwen rijden beter.**  
Minder ongelukken dus een lagere premie! Autoverzekering speciaal voor vrouwen. 1.761 personen vinden onna-onna leuk.

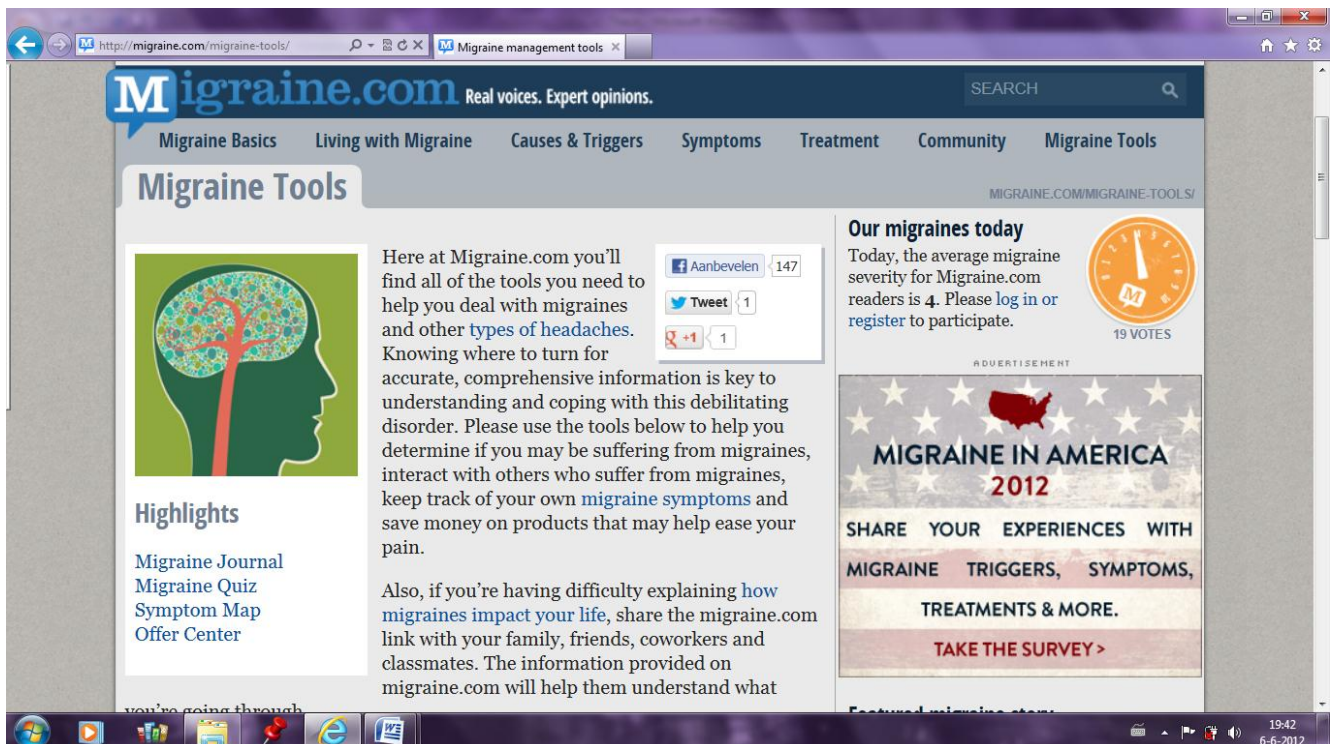
MEER ONLINE VRIENDEN (2)

Zoeken

## Appendix 2 – Migraine.com



The screenshot shows the homepage of Migraine.com. The browser address bar displays "http://migraine.com/". The page features a navigation menu with categories: Migraine Basics, Living with Migraine, Causes & Triggers, Symptoms, Treatment, Community, and Migraine Tools. A prominent banner for "Migraine Awareness Month" is displayed, with the text "SHARE, EDUCATE, PARTICIPATE: JUNE IS Migraine Awareness Month HELP MAKE MIGRAINES VISIBLE". Below the banner, there are social media sharing options for Facebook (3K), Twitter (1,113), and Google+ (32), along with a note that there are "Over 1,684 migraine articles". A featured article titled "Approaching June 2012 Headache & Migraine Blog Carnival Submission Deadline" is visible, posted by Diana Lee on June 6th, 2012. On the right side, there is a section titled "Our migraines today" with a clock icon showing "19 VOTES" and a survey link "TAKE THE SURVEY >". Below this is an advertisement for "MIGRAINE IN AMERICA 2012" with a similar survey link.



The screenshot shows the "Migraine Tools" page on Migraine.com. The browser address bar displays "http://migraine.com/migraine-tools/". The page features a navigation menu with categories: Migraine Basics, Living with Migraine, Causes & Triggers, Symptoms, Treatment, Community, and Migraine Tools. The main content area is titled "Migraine Tools" and includes a graphic of a brain with a tree-like structure. The text reads: "Here at Migraine.com you'll find all of the tools you need to help you deal with migraines and other types of headaches. Knowing where to turn for accurate, comprehensive information is key to understanding and coping with this debilitating disorder. Please use the tools below to help you determine if you may be suffering from migraines, interact with others who suffer from migraines, keep track of your own migraine symptoms and save money on products that may help ease your pain." Below this text, there are social media sharing options for Facebook (147), Twitter (1), and Google+ (1). A "Highlights" section lists: Migraine Journal, Migraine Quiz, Symptom Map, and Offer Center. On the right side, there is a section titled "Our migraines today" with a clock icon showing "19 VOTES" and a survey link "TAKE THE SURVEY >". Below this is an advertisement for "MIGRAINE IN AMERICA 2012" with a similar survey link.

http://migraine.com/forums/ Discussion Forums Director...

## Migraine.com Forums

MIGRAINE.COM/FORUMS/

### Hot topics

Read what the migraine.com community is discussing now - and join the conversation. Please [register now](#) or [sign in](#) to participate in a conversation.

**“ Dr Whyte -- I live in Minneapolis, MN. I'm [...]**  
 POSTED BY BOBBILYNN 17 HOURS, 48 MINUTES AGO  
 MIGRAINE HEADACHES DOCTORS - [READ MORE](#)

**Bond - research has shown that each of [...]**  
 POSTED BY ELLEN 2 DAYS, 11 HOURS AGO  
 NATURAL REMEDIES - [READ MORE](#)

VIEW OTHER RECENT CONVERSATIONS (224)

### Find a conversation


Speak your mind. Discuss specific symptoms, treatment, or any other migraine topic by choosing a conversation topic below.

### Causes & Triggers

- [Migraine Causes](#) 1 POST
- [Family History](#) 14 POSTS
- [Health History](#) 4 POSTS
- [Hormonal Changes](#)

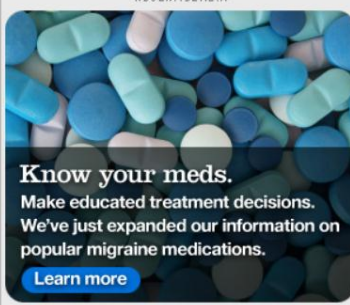
### Our migraines today

Today, the average migraine severity for Migraine.com readers is **4**. Please [log in](#) or [register](#) to participate.




20 VOTES

ADVERTISEMENT



**Know your meds.**  
 Make educated treatment decisions. We've just expanded our information on popular migraine medications.  
[Learn more](#)

### Featured migraine story

 "I spent years (a literal lifetime) going to every head pain clinic in the country and tried every migraine therapy..."

http://migraine.com/get-involved/ Get Involved with Migraine ...

**Migraine.com** Real voices. Expert opinions.

Migraine Basics Living with Migraine Causes & Triggers Symptoms Treatment Community Migraine Tools

## Get Involved

MIGRAINE.COM/GET-INVOLVED/

Although the symptoms of migraine attacks make many sufferers withdraw, the best way to cope with this disorder is to get involved. Support can be found in groups that meet in person or online, such as the information provided through migraine.com.


[Aanbevelen](#) 6

[Tweet](#) 1

[+1](#) 1


### Our migraines today

Today, the average migraine severity for Migraine.com readers is **4**. Please [log in](#) or [register](#) to participate.



21 VOTES

ADVERTISEMENT



**MIGRAINE IN AMERICA 2012**

SHARE YOUR EXPERIENCES WITH MIGRAINE TRIGGERS, SYMPTOMS, TREATMENTS & MORE.

[TAKE THE SURVEY >](#)

### See Also

- [The Migraine.com Blog](#)
- [Migraine.com on Facebook](#)
- [Follow Migraine.com on Twitter](#)

### Benefits of in-person support groups

- Face-to-face interaction with others who share the similar symptoms
- Participation in social activities with people who share your disorder
- Meeting people who are local who are also struggling with migraines
- Local migraine sufferers can provide referrals to local and regional specialists

### Benefits of online support groups

- No need to physically attend a meeting, which may conflict with other

## Appendix 3 – FB community migraine sufferers

The screenshot shows the Facebook interface for a group named "Migraine sufferers". The page header includes the Facebook logo, a search bar, and the user's name "Jacqueline". The group name "Migraine sufferers" is prominently displayed, along with navigation options like "Over de groep", "Evenementen", "Foto's", and "Bestanden". A banner image at the top features a purple ribbon and the text "HELI MAK MIGRAINE VISIBEL". Below the banner, there are options to "Bericht schrijven", "Foto/video", "Vraag stellen", and "Bestand uploaden". The group has 2,646 members. A post by "Amy Wittsell Dater" is visible, discussing her struggles with migraines and mentioning various treatments like triptans and abortives. The right sidebar contains sponsored advertisements for "ESPRIT: Zomerjeans!" and "CROCS Outlet Sale -40%". The left sidebar shows the user's profile and navigation menus for "FAVORIETEN", "GROEPEN", and "VRIENDEN".

This screenshot shows a discussion thread within the "Migraine sufferers" Facebook group. The main post is by "Beth Ratzburg", who writes: "The weather changes really play a number on my head and today was one of those days where I ended up sick due to a migraine". Below her post, several replies are visible:
 

- Linda J Zangari**: "last night and this morning is going to be my day. yuck. can't stay home from work either." (1 juni om 12:55)
- Beth Ratzburg**: "Don't you hate that...you are so sick with a migraine and still have to go to work and work through it somehow...how productive is that for you and for the company you work for." (1 juni om 13:47)
- Amira Matthews**: "Yesterday and this morning were the same for me. Hope you feel better." (maandag om 22:23 via mobiel)
- Beth Ratzburg**: "This morning I had the headache from ..... still have it as a matter of fact....." (maandag om 23:19)
- Stephanie Merrill**: "we all know what youre feeling :-( Gisteren om 2:15"

 A "Jillian Syrakowski" post is also visible at the bottom of the thread, discussing the difficulty of managing work with doctors in between appointments. The right sidebar shows a list of online friends, including Denise Schuurman, Dymphy Schuurman, Eline Vos, Femke Stoel, Fleur Buitelaar, Hilke Nieuwsma, Marloes Rauws, Richard de Groot, Sytske van der Zweep, and Willemijn Blom. The bottom of the page shows the Windows taskbar with the time 19:55 on 6-6-2012.

## Appendix 4 – Respondents

<b>Respondent</b>	<b>Sites</b>
A	migraine.com
B	migraine.com
C	migraine.com
D	migraine.com and migraine sufferers
E	migraine.com and migraine sufferers
F	migraine.com
G	migraine.com
H	migraine.com
I	migraine.com
J	migraine.com and migraine sufferers
K	migraine.com
L	migraine.com
M	migraine.com and migraine sufferers
N	migraine.com
O	migraine.com
P	migraine.com and migraine sufferers
Q	migraine sufferers