



FACULTY OF APPLIED ECONOMICS

Value co-creation in online health communities:
The role of participants' posts, network position and
behavioral patterns

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“The only true wisdom is in knowing you know nothing.” Socrates

A PhD trajectory is often compared to a journey, a quest for ‘holy wisdom’, or as some researchers describe it ‘a pilgrim’s progress’ characterized by confusion, avoidance of temptations, and loneliness. The confusion and temptations sound very familiar, but the loneliness? No, never! I’ve started this journey with some wonderful people by my side and during the process I have only met other inspiring persons who turned this journey into a life-changing experience. Now, at the end of my PhD journey, the time has come to say thank you for all their support.

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Chapter 1

Introduction

1.1. Research Problem and Context

Healthcare services affect quality of life more than any other services do (Berry & Bendapudi, 2007; Camacho, 2011). Due to aging populations and a parallel rise in chronic diseases, public expenditure on healthcare is rising and the financial foundations of the healthcare systems are weakening. In 2013, healthcare spending represented on average 8.9% of GDP for all OECD countries and it is expected to rise even more in the near future (D. Morgan, 2015). The increased pressure on cost reductions challenges policy makers to develop novel healthcare delivery models (Camacho, 2011; Wyke, 2011). Given the increased embeddedness of Internet in people's lives, digital services and in particular online health communities (OHCs) are put forward as innovative solution. Thereby, OHCs are defined as platforms that facilitate the gathering of individuals who interact on a common health interest (Lee, Vogel, & Limayem, 2003; Leimeister, Sidiras, & Krcmar, 2006). By sharing information on treatment and medication in the OHC patients satisfy each other's need to understand their disease and thereby create cognitive related value. However, by sharing emotions and giving emotional support patients satisfy each other's need for empathy and thereby create affective related value. These collaborations with peers in the OHC aid patients in coping with their condition which is in line with the definition of value co-creation. The latter is defined in research as "the benefit realized from integration of resources through activities and interactions with collaborators in the customer's service network" (McColl-Kennedy, Vargo, Dagger, Sweeney, & van Kasteren, 2012, p. 1; Vargo & Lusch, 2004a). Hence, patients co-create cognitive and affective value which aids in dealing with the everyday difficulties of their condition.

Various literature streams in marketing, services, and healthcare examined OHCs. Thereby, the authors focused on themes such as motives for participation (Welbourne, Blanchard, & Wadsworth, 2013), social practices (Loane & D'Alessandro, 2013b) and impact on health outcomes (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Yet, research regarding co-creation in OHCs is rather scant. Nambisan and Nambisan (2009) identified different models of patient co-creation in a healthcare context according to the nature of leadership (i.e. firm-led versus customer-led) and the nature of knowledge creation (i.e. knowledge creation versus knowledge sharing). Thereby online peer-to-peer support groups or OHCs as studied in this dissertation are put forward as one of the key value co-creation models in healthcare. The authors

emphasize the cost-effective addressing of peers' questions as the key outcome of OHCs, however they do not probe into the antecedents and nature of the value co-created. Zhao et al. (2015) build further on this study by examining the motives that drive patients' value co-creation activities in OHCs, conceptualized as knowledge contributions. However this rather simplified conceptualization omits the multidimensional nature of value co-creation in OHCs, as identified in previous healthcare research (Coulson, Buchanan, & Aubeeluck, 2007). Therefore, the overall aim of current dissertation is to investigate both cognitive and affective value co-creation in OHCs. In doing so, I distinguish and examine several antecedents of value co-creation and furthermore investigate the role of the OHC in the patient's service delivery network. Moreover, in this overall dissertation I aim to investigate value co-creation in OHCs on three levels: (1) the level of the community (i.e., OHC) (Chapter 2), (2) the level of the posting (Chapter 3), and (3) the individual level (Chapter 4). In a final study of this dissertation these three levels are integrated within an overall service delivery network (Chapter 5).

As a starting point to study this phenomenon there is a need to obtain a more global insight into the nature and types of OHCs that actually exist. Many healthcare organizations try to occupy and delineate their place in the OHC landscape. However, the diverse needs of different patients prevent setting up a single, one-size-fits-all community. Rather, the co-created cognitive and affective value in the OHC depends on several components such as the actors who participate in the OHC, the foundations of their relationships, and their activities. A prominent example is the OHC 'Patients Like Me' (PLM) which connects patients with healthcare professionals as well as with pharmaceutical companies and regulatory institutions to share experiences, assess new ideas and recommend alternative treatments. Due to the considerable variety in community components, healthcare organizations struggle with the implementation of such online services (Bain & Co., 2012; McKinsey & Co., 2014). A finer-grained understanding of the features would offer community hosts insights on how to tailor communities to various needs and market segments. Therefore, the first aim of this dissertation is to *investigate the different community features that determine the value creation in an OHC*.

Next, within the OHC, we need to zoom in on the other units of analysis. On the level of the online postings we consider the study of the community members' contributions in the OHCs. On the individual level we consider the study of the community members' structural network

characteristics within the OHC. We adopt an information processing perspective to explain how patients might determine the characteristics of their online postings and consequently the nature of the value co-created. Hence, to gain from OHCs, managers need insights into how online posting characteristics lead to value (i.e. cognitive and affective) and moreover how they can steer and manage the value co-creation (Mahr & Lievens, 2012). A second aim of this dissertation is to *examine drivers for value co-creation in OHCs on a posting level*.

We focus on the individual level by considering community members as part of a social network. Indeed, the way they are embedded in a social network (i.e., the OHC) might determine their access to knowledgeable, supportive peers and consequently affect the nature of the value they co-create in the OHC. Since the ability to identify and integrate valuable members into the OHC is considered to be a main competitive advantage (Prahalad and Ramaswamy 2004), more insights are needed concerning which social network structure is most efficient to stimulate cognitive and affective value co-creation in a healthcare context (Kleijnen, Lievens, de Ruyter, & Wetzels, 2009; Trusov, Bodapati, & Bucklin, 2010). Therefore, a third aim of this dissertation is to *examine community members' social network structure as a driver for value co-creation in OHCs*.

OHCs and their respective components (cfr. Studies mentioned above) are part of a service delivery network (SDN) and not used in isolation, but rather in the context of a network of supportive relationships outside the virtual community. Imagine a patient who consults an OHC to check his symptoms before diagnosis, then consults his general practitioner (GP), receives emotional support from family and returns to the OHC to provide advice to peers. Hereby, the OHC is part of the patient's service delivery network that contains traditional service providers as well as public and private sources. Given changing patient needs across disease steps, the components of the SDN might change over time. Hence, managers and policy makers need to understand the role of the OHC across several disease steps in order to facilitate its integration in the healthcare service system and create a satisfying patient service experience (S. Morgan & Yoder, 2012). Therefore, a fourth aim of this dissertation is to *examine how OHCs are integrated in the patient's service delivery network*.

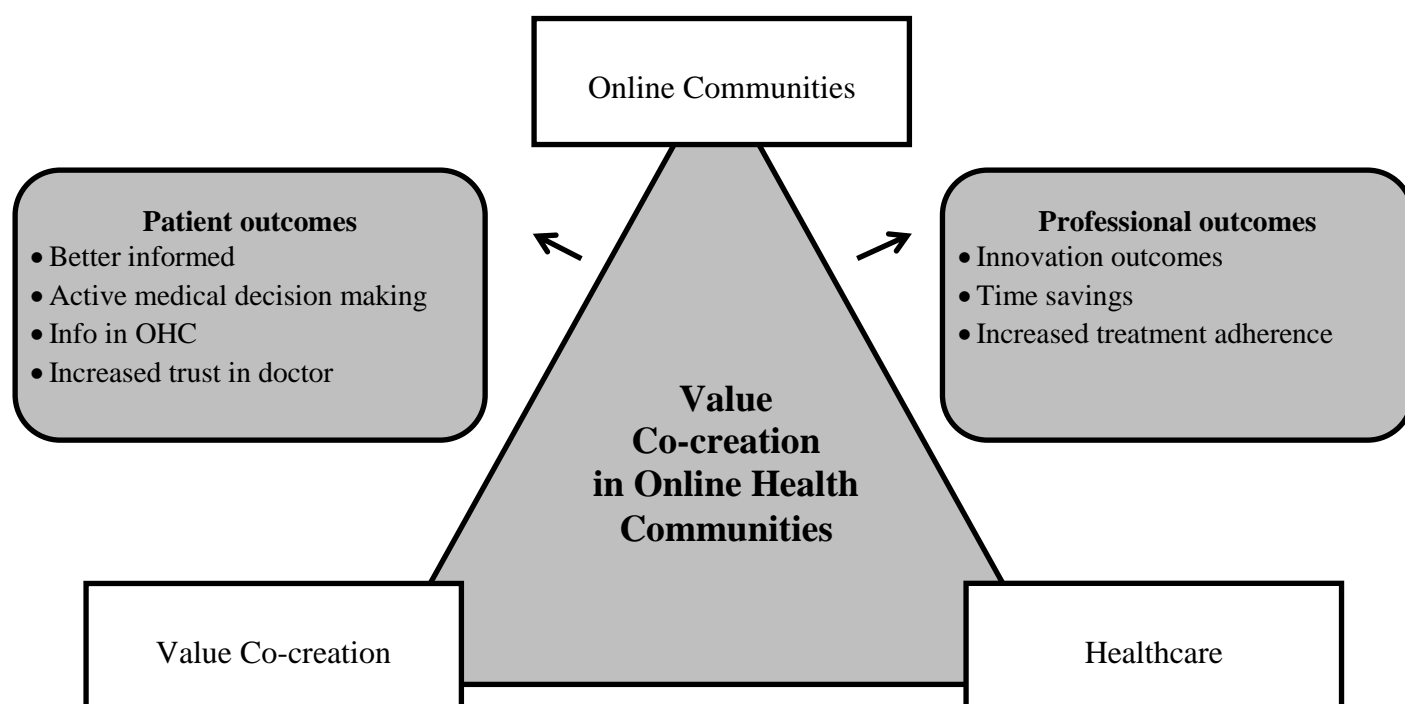
To answer my research questions, multiple literature streams are integrated. By combining emergent literature on; (1) value co-creation; (2) healthcare and (3) online communities I am able

to investigate the complex phenomenon of value co-creation in OHCs and contribute to each of these literature streams. In the following sections I elaborate on this dissertation's conceptual foundations, present an outline of the different chapters and list the main contributions of this dissertation.

1.2. Conceptual Frameworks

This dissertation is built upon three literature streams: (1) literature on value co-creation; (2) literature on healthcare and (3) literature on online communities. Each of these different streams provides a lens to examine value co-creation in OHCs. Furthermore, in Figure 1-1 I included multiple outcome variables that demonstrate the relevance of value co-creation in OHCs for patients as well as for healthcare professionals. The underlying models and definitions from these theoretical lenses are discussed in each of the different chapters. In this section, I provide an overview of the three overarching conceptual themes.

Figure 1-1 Conceptual foundations

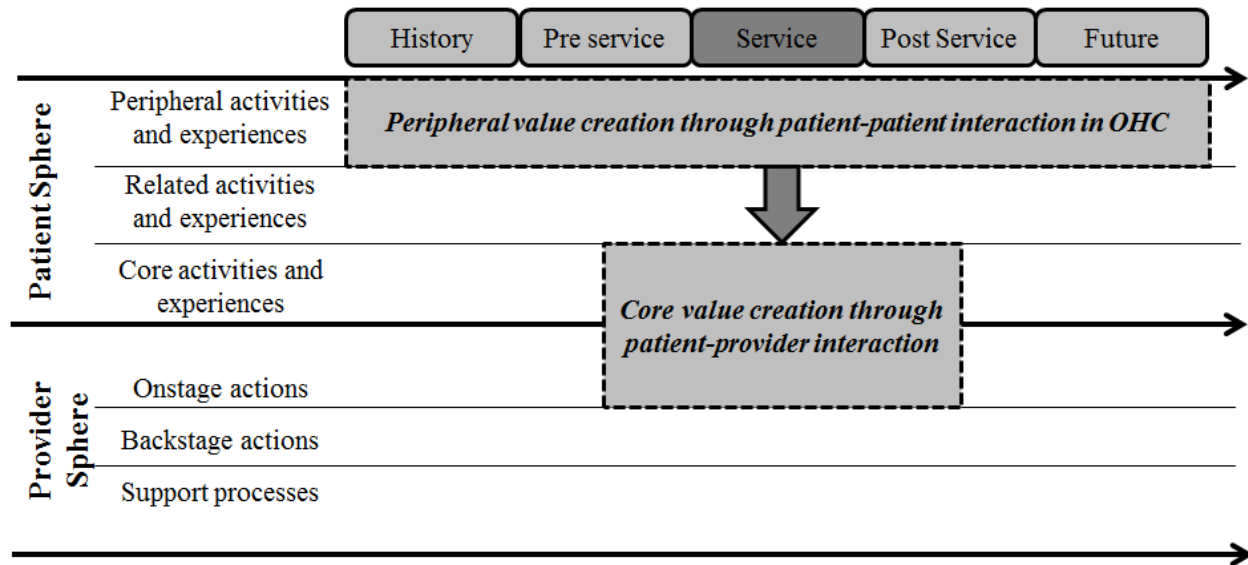


1.2.1. Customer Co-creation

My dissertation adopts customer co-creation as a context to examine OHCs. Hereby, I focus on the patient's network of peers in OHCs as collaborators in his healthcare management. With a few notable exceptions, previous co-creation research does not recognize patient-to-patient communities as co-creation platforms. By adopting a service-dominant logic (S-D logic), existing research focuses on the interaction between patients and service providers, thereby mainly adopting a provider perspective. In this logic, consumers are regarded as partners or even temporary employees of the organization. However, recently a new emerging consumer-dominant logic (C-D logic) advocates an emphasis on the consumer and offers a perspective to study patient-to-patient communities as a source of co-creation (Heinonen et al., 2010). The C-D logic considers healthcare consumers as central actors in the co-creation paradigm, rather than the service provider or the interaction. Hereby, value is considered as being embedded in the practices of the consumer. This means that value extends beyond the interactive process between provider and patient, and consequently beyond the visibility of the healthcare provider (Rihova, Buhalis, Moital, & Gouthro, 2013). Healthcare consumers receive therapies and treatments from the service provider (i.e. core activity and experience), but they also engage in other activities such as participation in OHCs (i.e. other activity and experience) which add value to the core experience (Keeling, Laing, & Newholm, 2015; Kivits, 2006). Consider for example a patient who has to undergo a complex surgery he is not familiar with. By asking questions and receiving information from knowledgeable peers, the patient will be better prepared and experience the surgery in a different way. Figure 1-2 represents how co-creation in OHCs is positioned in the research space relative to patient-provider co-creation. Consumers act as partners of their service providers during the development and delivery of core healthcare activities. However, since patients live in a social context, they perform other activities such as participation in an OHC, besides the interaction with their provider. All these activities carried out by the consumer, independent from the provider, will have an impact on his core value experience. I consider participation in OHCs as one of the peripheral activities that shape the core value experience of the healthcare consumer. Although these peripheral activities do not directly involve interaction with the service provider, the C-D logic states that through patient-patient interactions value is created and hence co-creation is taking place. In the current dissertation a broad perspective is adopted to interpret value co-creation, meaning that both active (i.e. posting a message) and

passive (i.e. reading a message) participation in OHCs is considered to be co-creation. Furthermore, every single posting in an OHC is interpreted as the result of a co-creation effort given that it is a pivotal part of a community experience.

Figure 1-2 Co-creation research space



Note: Adapted from Heinonen et al. (2010)

1.2.2. Online Communities

The proliferation of Internet access has facilitated the rapid growth of online communities. The impact of online communities is apparent in every aspect of customers' lives ranging from marketing and business to social and educational activities (Chiu, Hsu, & Wang, 2006). Since customers grew comfortable with using online communities for multiple purposes, they recently began to use them for complex and sensitive issues such as healthcare (McKinsey & Co., 2014). These OHCs are actually the platform in which patient co-creation takes place. The community setting allows for patients to exchange knowledge and support one another (Keeling et al., 2015). Patients experience a need to connect, learn and engage with others in the community throughout their disease stages. Foremost, throughout the entire period patients also interact with other healthcare providers. As a result, these health communities, their members (i.e., patients) as well as the content (i.e., postings) is constantly evolving and changing. Among the challenging research opportunities is the question "What type of value is being created?" and "How can

relationships between patients enhance these types of value creation?” The latter can be explored by visualizing and analyzing the network structure of patients within the OHC.

1.2.3. Healthcare

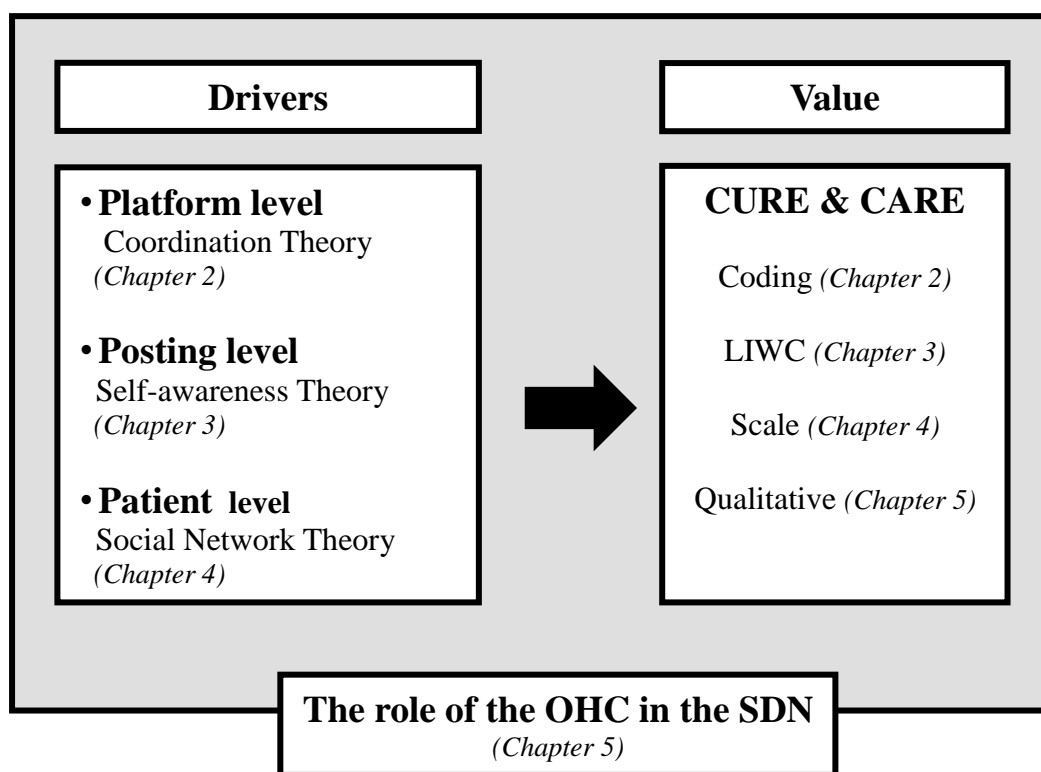
Healthcare services have distinct characteristics which might differ from any other service. Healthcare customers are ill, under stress and sometimes even reluctant and frightened to receive medical services (Berry & Bendapudi, 2007). Nevertheless this reluctance, adherence to the prescribed treatment might make a difference between life and death for a patient. OHCs aid patients in regaining trust in their treatment and consequently might increase treatment adherence which is a crucial factor for the healthcare industry. Since healthcare services contain credence properties patients rely on few cues to assess the service. This state of imperfect information introduces a high level of perceived risk (Parasuraman, Zeithaml, & Berry, 1985; Zeithaml, 1981). Participation in OHCs might reduce this perceived risk by providing the opportunity to connect to peers who are similar in terms of disease, disease stage and prescribed treatment (Leimeister, Schweizer, Leimeister, & Krcmar, 2008). The information that patients receive from their peers through co-creation efforts makes the service more tangible and consequently might increase trust in the provider as well as in the treatment (Kivits, 2006). Furthermore, democratized access to information via OHCs fostered a shift in the healthcare industry from a white-coat model with limited patient empowerment to an active patient paradigm in which patients actively participate in treatment decisions (Camacho, Landsman, & Stremersch, 2009). Hence, online collaboration enables patients to learn from each other and develop a wide range of skills and competences to make more informed decisions (Jayanti & Singh, 2010). Thereby patients co-create two distinct value types which are important for treatments' therapy efficacy and patients' well-being (Apesoa-Varano, Barker, & Hinton, 2011). First, patients co-create so called *cure*-related value, which is functional information that helps them better understand their disease and learn about new treatments. Second, emotional support stems from so called *care*-related value, which conveys empathy to help patients in bearing the burden of the disease and coping with resulting stress (Apesoa-Varano et al., 2011). Despite the importance of cure and care for patients' well-being, few studies looked into their emergence under the active patient paradigm (McColl-Kennedy et al., 2012; Ong, De Haes, Hoos, & Lammes, 1995). Hence, by

studying the nature of the value co-created in OHCs and its drivers, this dissertation contributes to the understanding of the active patient paradigm.

1.3. Dissertation Outline

The consequent chapters of this dissertation contain four studies that examine several aspects of value co-creation in online health communities. Figure 1-3 provides an overview of the research projects.

Figure 1-3 Overview of research project



Since the value types are operationalized in a different way across chapters, I provide an overview in Table 1-4. In the first three studies of this dissertation an active perspective is adopted which aligns with ‘co-creation’. Hence, active participation in an OHC involves posting messages rather than passively reading them. Thereby, value is created in terms of cure (i.e. cognitive) and care (i.e. affective). However, in the final study passive participation is included as well, which aligns more with ‘patient experience’. Here, active and passive participation, established as reading and posting, is considered to create value on an emotional, cognitive and behavioral level. Consequently, co-creation is considered to be a part of the patient experience.

Table 1-1 Operationalization value types

	Value types	Perspective	Operationalization
Study 1 (Chapter 2)	Cure and care	Active participation (i.e. posting)	Coding on a 3-point scale
Study 2 (Chapter 3)	Cure and care	Active participation (i.e. posting)	Linguistic Inquiry and Word Count (LIWC)
Study 3 (Chapter 4)	Cure and care	Active participation (i.e. posting)	Scale development
Study 4 (Chapter 5)	Emotional, cognitive and behavioral value	Passive participation (i.e. reading and posting)	Qualitative interpretation (i.e. open and axial coding)

1.3.1. Chapter 2

This chapter draws on coordination theory to develop *a framework investigating patterns of online health communities*. Qualitative and quantitative techniques are applied to detect similarities and differences in a sample of 50 OHCs. A categorical principal component analysis combined with cluster analysis reveals 4 distinct community configurations. The analysis exposes differences in the degrees of cognitive and affective value creation, the types of community activities, the involved patients, professionals, and other stakeholders; and the levels of data disclosure by community members. Four community configurations emerge: basic information provider, advanced patient knowledge aggregator, systematic networked innovator, and uncomplicated idea sharer. Their distinct features determine communities’ capacity to internalize and externalize knowledge, which ultimately determines their value creation. The value types cure and care are interpreted as active participation in the OHC and operationalized via two 4-point scales.

1.3.2. Chapter 3

In this study, I zoom in on *the characteristics of the online posting in the online health community*. In particular, this research adopts self-awareness theory to investigate the patient’s reference frame (i.e. self versus other) which constitutes a processing mechanism of information in online communities and its impact on value creation. The findings show that information gathered through the patient–doctor encounter and processed via self-referencing enhances cognitive related value, but limits affective oriented value co-creation. Other-referencing does exactly the opposite as it creates a barrier for cognitive related value while stimulating affective related value. The patient’s experience with the community (i.e. the number of online postings

they share) plays a pivotal role because it largely moderates the impact of self- and other-referencing on cognitive and affective related value. Overall, the findings show the potential of OHCs to identify and address unmet patient needs (e.g., need for emotional support and additional information), but also the critical role healthcare professionals may play in affecting the information in the OHCs through traditional healthcare encounters. In this chapter, the value types cure and care are interpreted as active participation in the OHC and operationalized via the automated text analysis tool LIWC (i.e. Linguistic Inquiry and Word Count).

1.3.3. Chapter 4

In this chapter, I adopt *a social network perspective to understand how value is being co-created in OHCs*. Hence, a patient's network position (i.e. connectedness and integration) might influence his behavior and consequently his value co-creation potential. I test my hypotheses on data gathered in three OHCs which contain 467 community members in total who posted 1534 online postings altogether. To do so, I develop and validate a scale to measure the items that community members use in assessing the level of cognitive and affective related value. The findings indicate that to ensure cognitive and affective related value co-creation in the OHC, members should be highly connected, but poorly integrated in their network. The value types cure and care are interpreted as active participation in the OHC and operationalized via the scale I developed in this chapter.

1.3.4. Chapter 5

The final project in this dissertation zooms out on *the role of the OHC in the patient's service delivery network (SDN) across the patient journey*. An online focus group was set up to query 124 patients about their experience with various service providers during the disease journey, including the OHC. Coordination theory is used as a theoretical lens to study the SDN as a cooperative system and aids in delineating the role of the OHC. Qualitative data is analyzed by means of manual content analysis and complemented with the automated content analysis tool Leximancer which allows visualization of the text data. The findings suggest a vital role for the OHC across activities in the patient journey and identify opportunities for collaboration in the SDN. The value types in this chapter (i.e. emotional, cognitive and behavioral value) are

interpreted as active and passive participation in the OHC and operationalized via qualitative interpretation.

1.4. Contributions

In this dissertation I investigate value co-creation in OHCs. Thereby, I study the role of participants' postings, network position and behavioral patterns. In doing so, this dissertation contributes to several literature streams.

First, this dissertation entails important implications for emergent literature regarding customer co-creation in OHCs. Value co-creation refers to a "benefit realized from integration of resources through activities and interactions with collaborators in the customer's service network" (McColl-Kennedy et al., 2012, p. 1; Vargo & Lusch, 2004a). Existing literature regarding co-creation in the healthcare sector reveals that patients engage in several activities ranging from merely accepting information from the service provider to actively seeking and sharing information with others and assisting with redesigning treatment programs (McColl-Kennedy et al., 2012; Nambisan & Nambisan, 2009; Ouschan, Sweeney, & Johnson, 2000). These activities might take place across multiple settings such as traditional medical encounters, daily personal interactions, or even in OHCs (Prahalad & Ramaswamy, 2004a). However, research investigating patient co-creation in OHCs is rather scant and omits to recognize and investigate the multidimensional nature of the value co-created. The current dissertation adds to this growing literature stream by delineating how peer-to-peer interactions in OHCs trigger cognitive and/or affective value co-creation.

Second, I contribute to the healthcare innovation literature by probing into innovative ways of delivering healthcare services through peers rather than through medical experts. Recent developments in ICT accelerated the shift from a 'white coat' model towards empowerment and participation of healthcare customers (i.e. patients) (Camacho et al., 2009). Moreover, OHCs might be monitored to identify innovation potential which might reduce the innovation cost and time to market and consequently affect healthcare costs in general (Mahr, Lievens, & Blazevic, 2014). Furthermore, the communities can serve as an additional channel to provide certain services like for example support services. If customers can be directed towards a patient community to discuss problems and provide solutions, healthcare organizations can focus their

resources on more complex and knowledge-intensive queries (Nambisan & Nambisan, 2009). Additionally, cognitive and affective value co-creation with peers might empower patients to actively participate in treatment decisions which contribute to treatment compliance and therapy efficacy. However to fully grasp the potential of these innovative healthcare solutions more research is needed regarding their functioning. To do so, the current dissertation develops a theoretical framework that identifies the relevant drivers on a community, posting and individual level and relate them to cognitive and affective value co-creation.

Third, I contribute to OHC literature by combining a netnographic approach with text mining techniques to examine the content of online postings. Researchers always used a diversity of methods to study patients (i.e. healthcare consumers), ranging from individual interviews and surveys to focus groups and market oriented ethnography (Goldman, 1962; Kozinets, 2002; Robinson & Agisim, 1951). Nevertheless, these methods come with some major disadvantages. By approaching participants in an intentional way unobtrusive observation of naturally occurring behavior is limited. Especially in a healthcare context where researchers probe into sensitive information, respondents might be hesitant or resistant to participate in surveys or focus groups. Furthermore, there is a limitation of collection frequency and the risk of introducing a response bias with respondents giving social desirable answers. The current dissertation applies netnography to gather publicly available information from OHCs and combines manual content analysis with automated content analysis and text mining to overcome the limitations of existing OHC research (Kozinets, De Valck, Wojnicki, & Wilner, 2010).

Chapter 2

Determining Online Health Community Configurations and their Role during Value Creation: A Coordination Theory Perspective ¹

¹ An article based on this chapter is under review at the *Journal of Service Management*.

An earlier version of this chapter was presented at the *24th Annual Frontiers in Service Conference* in San Jose, USA.

2.1. Introduction

Patients increasingly use online services to gain insights into and share experiences about their health conditions. About 72% of US Internet users seek health information online, and 16% of them search for peers who share similar health concerns (Pew Research Center, 2013). These searches for health information and peer-to-peer communication online are fueled by patients' struggles to satisfy their varied disease-related needs. When confronted with a diagnosis, patients often ask for explanations of the disease and treatment guidance ('cure'), but also want expressions of empathy or shared concern ('care') (Hoch & Ferguson, 2005; Johnson & Ambrose, 2006). The distinction is reflected in the services literature where consumers extract cognitive and affective benefits from their relationship with the service providers, both in an offline (Beatty, Mayer, Coleman, Reynolds, & Lee, 1996; Gwinner, Gremler, & Bitner, 1998), and an online setting (Dholakia, Blazevic, Wiertz, & Algesheimer, 2009; Mathwick, Wiertz, & De Ruyter, 2008). However, healthcare services considerably differ from any other service because they are often unwanted, although adherence to treatment can make a difference between life and death (Berry & Bendapudi, 2007). Time and budget constraints leave healthcare professionals only partly able to address diverse patient needs (LaVela & Gallan, 2014); doctors often schedule 11-minute time intervals for patient consultations, which suggests questionable healthcare quality (National Center for Health Statistics, 2010). The need for professional distance also prevents healthcare professionals from building overly empathic relationships with patients (Apesoa-Varano et al., 2011). Thus many patients leave their doctors' offices with an abundance of unanswered questions and insufficient opportunities to share their feelings (Johnson & Ambrose, 2006).

Because online health communities (OHCs) provide access to information and coordinate social interaction, they constitute an alternative solution for patients' needs, such that they likely improve the well-being of individuals and society as a whole (Zhao et al., 2015). In the online community *patientslikeme.com*, 300,000 members discuss more than 2,500 healthcare conditions (PLM, 2013). Such peer-to-peer interactions might complement traditional face-to-face encounters with medical professionals (Kivits, 2006). However, the diverse needs of different patients prevent any single, one-size-fits-all community; rather, cure- and care-related value in a community depends on who participates (e.g., patients, doctors, industry experts), the foundation of their relationship (e.g., trust, reciprocity), and their activities (e.g., sharing experiences, assessing new ideas, recommending alternative treatments). Many

healthcare organizations struggle with the interdependencies and trade-offs across these components when they attempt to implement online services (Bain & Co., 2012; McKinsey & Co., 2014). The value propositions of OHCs highlight the creation of cure- and care-related value which aims at patient's well-being. A finer-grained understanding of the features offers community hosts insights on how to tailor communities to various needs and market segments. Hence, this research adopts a provider perspective and investigates the different community features that determine the value proposition of an OHC.

This paper offers coordination theory, proposed by Malone and Crowston (1990) as a theoretical lens. Coordination theory has been applied in various research disciplines (e.g., computer science, sociology, political science, management science, systems theory, economics, linguistics, and psychology) to examine collaborative systems. The four components of this theory (i.e. goals, activities, actors, and interdependencies) aid in capturing the complexity of coordinating online health communities. Thereby, the components provide a lens to examine the elements of online health communities and how they interact. Given the theory's particular focus on computer-supported cooperative work, the authors consider this framework as very suitable to examine the underlying mechanisms of online health communities. In this view, an OHC is a knowledge-based, cooperative system of value creation that relies on multiple community components to coordinate participants' interactions. These four components (i.e. goals, activities, actors, and interdependencies) feature inherent trade-offs and conflicts. First, the *goal* of the community can be oriented towards cure- and/or care-related value creation. Prior healthcare research has established the importance of both dimensions for a patient's well-being, yet no agreement exists in terms of whether these components are synergistic or conflicting (Apeso-Varano et al., 2011; De Valck, Bensing, Bruynooghe, & Batenburg, 2001). Second, community *activities*, such as information diffusion, social exchange, or idea development, demand different functionalities, motives, and skills (Nambisan & Nambisan, 2009). If a single community combines several activities, coordinative challenges arise for community management, which may hinder its ability to meet members' needs. Third, different *actors* or platform users might be targeted for participation. Greater diversity produces more diverse opinions, which enriches community content, but greater similarity ensures a common interest to facilitate communication (Phelps, Heidl, & Wadhwa, 2012). Fourth, to manage online collaborations, several *interdependencies* between community members and their activities must be taken into account, such as trust-building mechanisms. The extent to which

a community member discloses personal information may determine the level of trust among community members (Ebner, Leimeister, & Krcmar, 2009) and thus the creation and amount of sharing of valuable knowledge (Ridings, Gefen, & Arinze, 2002). But community members likely are wary about sharing personal details, due to their privacy concerns (National Center for Health Statistics, 2010). In summary, the various, inherent conflicts noted in previous research prevent a single solution to emerge and instead demand subtle orchestration across these community components. This might explain why extant research on online peer-to-peer support has not reached a consensus regarding its effects on health and social outcomes (Eysenbach et al., 2004).

The authors probe the heterogeneous nature of online health communities by investigating the community components driving cure- and care-related value creation. The focus is on the characteristics of communities in which patients interact, and thus the authors strive for three main contributions. First, this paper sheds light on the diverse landscape of digital service provision in the healthcare industry by identifying clusters of value creation for patients in digital communities. In doing so, the authors contribute to a key services research priority by providing insights into the coordination of value co-creation in a collaborative context (Ostrom, Parasuraman, Bowen, Patrício, & Voss, 2015). Through the lens of coordination theory, the authors systematically compare and describe OHCs and their features. Thereby, four clusters are identified with distinct community components (i.e. goals, activities, actors, and interdependencies) that determine their potential for cure- and care-related value creation. Categorical principal component analysis is well suited for investigating complex social phenomena such as online health communities to detect similarities and differences among them (Jick, 1979; Odekerken-Schröder, Hennig-Thurau, & Knaevelsrud, 2010). By combining qualitative and quantitative techniques this research approach is able to overcome the pitfalls of both methods. Second, the authors advance research on the relationship between cure- and care-related value created in a digital setting and its drivers. Cure and care represent key dimensions of patients' knowledge (Apeosa-Varano et al., 2011; De Valck et al., 2001), but research on their simultaneity in healthcare is scarce. However, a distinct characteristic of healthcare services in comparison with other services is the customer's need for a 'whole person' service. Hence, simultaneous addressing both cure- and care-related needs (Berry & Bendapudi, 2007). This research attempts to shed light on their synergistic or conflicting nature, to determine which community features affect them. Accordingly, the authors advance coordination theory by considering not only cure-related goals, but also care-

related goals of coordinating an online health community and theoretical components that coincide with both types of goals. In doing so, this study investigates the development of technology-enabled services to improve patients' well-being, thereby contributing to transformative service research (Ostrom et al., 2015). Third, the authors probe the inherent trade-offs that characterize key components of coordination theory in the context of OHCs. By identifying clusters of communities, a better understanding of the different characteristics and interdependencies among and within components is obtained. On a broader level, this research advances service managers' understanding of how empowered patients might contribute to value creation and the role of online communities in the healthcare service system which is identified as a service research priority by Ostrom et al. (2015).

To achieve these contributions, the paper starts with a literature review on patient involvement, online health communities, and coordination theory. Next, the authors describe the methodology, identify clusters of health communities, and elaborate on their features. Finally, the authors discuss the findings, formulate key implications for theory and practice, and offer suggestions for further research.

2.2. Literature Review

2.2.1. Involvement of Patients in Healthcare Services

The healthcare landscape traditionally has been dominated by five stakeholders—regulators, providers, payers, suppliers, and patients—among which patients had the least power (Stremersch, 2008). Technological advances prompted a shift from a healthcare model dominated by professionals towards a patient-centered model, in which patients and professionals collaborate to create a service that provides the most optimal healthcare solution for each case (Camacho et al., 2009). This new paradigm of patient empowerment entails “an enabling process through which individuals or groups take control over their lives and managing disease” (Demiris, 2006, p. 186). As an illustration of its emergence, a recent study shows that 13% of US healthcare customers maintain electronic health records, independent of their doctors' (Deloitte, 2014). The increasing involvement of patients as active participants in their treatment choices is part of a global marketplace trend towards customer participation (Prahalad & Ramaswamy, 2004a; Vargo, 2008), such that the customer is no longer a passive recipient of services, but rather serves as an active co-creator of value. Firms thus need to offer active customers opportunities to engage in extensive value co-creation (Jaakkola & Alexander, 2014). Despite the emergence of patient value co-

creation as a key service research priority (Ostrom et al., 2015), few studies investigate how online communities can be coordinated and thereby serve as platforms for patient involvement (Zhao et al., 2015). Yet, the collaborative context of value co-creation, which is increasingly characterized by multi-actors and networks, adds to its complexity and asks for a significant coordination effort. Hence, more research is needed to clarify how coordination should take place (Ostrom et al., 2015).

Digital services provide healthcare customers with easy access to healthcare information and facilitate peer-to-peer connections so they can exchange experiences and social support (Cline & Haynes, 2001). Shared information may serve as input for the patient–professional encounter, such that it might encourage active patient involvement during service delivery and foster shared decision making (Gustafson et al., 1999; McColl-Kennedy et al., 2012; Sweeney, Danaher, & McColl-Kennedy, 2015). Previous research also concludes that patient involvement leads to favorable outcomes, such as more trust in the health professional, higher patient satisfaction, better adherence to treatment, and overall increased health status (Camacho et al., 2009).

2.2.2. Online Health Communities

Online communities gather individuals who interact on a common interest, facilitated by a technical platform (Lee et al., 2003; Leimeister et al., 2006; Mahr & Lievens, 2012). Research regarding online health communities can be classified around the components of coordination theory, hence goals, activities, actors, and interdependencies (see Table 2-1). While previous research mainly focuses on one component of coordination theory, this study aims to provide an overview of the components including their respective trade-offs.

Table 2-1 State-of-the-art online health community research

Classification	Theme	Authors
Goals	<ul style="list-style-type: none"> • Health outcomes • Patient-provider relationship • Integration online and offline services • Perceived (dis)advantages 	Turner et al. (2001); Colvin et al. (2004); Eysenbach et al. (2004); Kivits (2006); McMullan (2006); Stevenson et al. (2007); Dannecker & Lechner (2007); Fang et al. (2008); Keeling et al. (2015)
Activities	<ul style="list-style-type: none"> • Innovation • Knowledge creation • Information provision • Connections to peers 	Cline & Haynes (2001); McMullan (2006); Nambisan & Nambisan (2009); Adams (2011); Bullinger et al. (2012); Vicdan & Dholakia (2013); Zhao et al. (2015);
Actors	<ul style="list-style-type: none"> • Impact of participant characteristics • Motives for participation 	Leimeister et al. (2006); Leimeister et al. (2008); Mo et al. (2009); Welbourne et al.

	<ul style="list-style-type: none"> • Precursors for relationship formation (2013) • Types of actors 	
Interdependencies	<ul style="list-style-type: none"> • Trust-building mechanisms • Quality assurance procedures • Design issues • Social practices 	Cline & Haynes (2001); Leimeister et al. (2005); Maloney-Krichmar & Preece (2005); Loane & D'Alessandro (2013b)

OHCs drive customer involvement through information provision, knowledge creation, and connections to peers. Firms in various sectors, including high-tech (e.g., Dell), toys (e.g., Lego), and automotive (e.g., Fiat), rely on online communities to enhance customer involvement. Yet, OHCs are unique. These customers are often ill and discuss services they need, but do not want (Berry & Bendapudi, 2007). Therefore, they tend to contain more affective content than online discussions in other sectors. Furthermore, the creation of trust is crucial (Ebner, Leimeister, & Krcmar, 2004); discussing life-threatening diseases or health-related taboos demands trust in other members' competence and goodwill.

In OHCs, patients share information with peers, who then process that information in light of their existing stock of knowledge. Through discussions of their interpretations in the online community, they create new knowledge (Richard P. Bagozzi & Dholakia, 2002; Nonaka, 1994). Established social relationships with peers then provide trust and nurture future information sharing and knowledge creation (Ridings et al., 2002). Therefore, OHCs constitute knowledge creation communities, with knowledge defined as "information that is relevant, actionable, and based at least partially on experience" (Leonard & Sensiper, 1998, p. 113). Explicit knowledge is codified and transmittable in formal language; tacit knowledge has a personal quality, which makes it hard to formalize and communicate (Nonaka, 1994). OHCs facilitate the interplay between explicit and tacit knowledge by providing tools to externalize tacit knowledge and internalize explicit knowledge.

Interactions in a community might involve different healthcare stakeholders, including regulators, providers, payers, suppliers, and healthcare customers (e.g., patients, families, informal caregivers), and in general they center on brands, products, and services (McWilliam, 2012). The common interest, which provides the community's main reason to exist, relates to healthcare activities such as patient or staff education, providing support, discussion of diseases and treatments, sharing of documents, or consulting with experts (Demiris, 2006). In summary, OHCs are online services that employ social technologies and tools to enable knowledge creation and sharing among healthcare stakeholders. For this

research, the authors focus on patient-centered communities in which patients extract value in the form of new knowledge, created by discussing information shared in the community. Still, other healthcare stakeholders, beyond patients, might participate in the community, by adding specialized knowledge or to learn from patients.

2.2.3. Cure- and Care-related Value Creation

Patients process and interpret information shared online. Through social interaction and discussion, they create value in the form of new knowledge for patients (Dholakia et al., 2009), as either cure- or care-oriented value (Chronister, Johnson, & Berven, 2006; Zainuddin, Russell-Bennett, & Previte, 2013). First, cure-oriented value relates to facts, advice, and guidance that support patients' knowledge about health-related issues. Better informed and more knowledgeable patients are more inclined to take an active role in their healthcare management and implement their treatments (Camacho et al., 2009). These patients may benefit from their active involvement in decision-making processes, because the chosen therapy will better fit their treatment and desired outcomes, which should improve their general health status (Camacho et al., 2009). Second, care-oriented value relates to affection, listening, and empathy (De Valck et al., 2001; Ong et al., 1995), which expands patients' knowledge by helping them vent their feelings, bear the burden of the disease, and cope with the resulting stress (Apesoa-Varano et al., 2011). This value can evoke optimistic self-beliefs in patients, be beneficial for recovery, and encourage patients to cope with discomfort or relapses (Schulz & Schwarzer, 2004). Hence, cure- and care-related value creation constitutes the foundation of an online community's value proposition. This is in line with literature on the patient-physician relationship that states that patients experience a need for cure (i.e. need to solve the illness problem) and care (i.e. need for emotional support). To satisfy these needs the physician should perform instrumental tasks such as prescribing medication and exchanging information as well as display affective behavior such as the expression of empathy and reassurance (Roberts & Aruguete, 2000). Thereby, care is uniquely linked to affective needs since service literature links care-oriented value to affection, listening and empathy while cure-oriented value relates to facts, advice, and guidance that support patients' knowledge about health-related issues (Beatty et al., 1996; Gwinner et al., 1998). Since online health communities complement the task of the physician, similar goals are identified as value proposition.

2.2.4. Drivers of Value Creation in Online Health Communities

The complexity of digital services, which involve various processes of interaction among different actors, demands a more fine-grained view of value creation in online communities (Chandler & Lusch, 2015). The authors use coordination theory as the theoretical lens as it has been used to describe computer mediated environments coordinating large groups such as universities and government (Euerby & Burns, 2014). In line with this theory OHCs are conceptualized as complex service systems that hinge on four components.

The first component, *goals*, relates to a community's objectives, namely, creating cure- and care-related value for patients. The outcome of participation in an online community is a new stock of knowledge that patients can use to deal with their disease. To combine information in the community with their preexisting knowledge base, patients interpret information, discuss it online, and create value in the form of a new stock of knowledge, which is either cure or care oriented (Nambisan & Nambisan, 2009). Cure-related value is connected to knowledge, which helps patients better understand their disease and learn about new treatments. Care-related value consists of knowledge, which helps patients bear the burden of the disease and cope with stress (Apesoa-Varano et al., 2011). Both value dimensions must be present and coordinated in the online community, but they can be both synergistic or conflicting (Apesoa-Varano et al., 2011; De Valck et al., 2001).

The second component, *activities*, relates to different practices that contribute to the goals of cure- and care-related value creation. Knowledge creation is a social rather than an individual process (Richard P. Bagozzi & Dholakia, 2002), so health communities need activities in place to support social interaction, which leads to knowledge creation. Sharing information about the community status, such as the most popular topics, draws members to relevant content that can function as a building block for further knowledge creation. Community hosts might help patients connect by providing online tools, such as forums and chat sessions that encourage patients to share data (Lee et al., 2003). Community members might directly or indirectly contribute to the benefit of third parties. For example, a healthcare provider who carefully listens to patient-provided information can obtain a better understanding of patient needs and ultimately innovate products and services that better meet these consumers' requirements (Pralhad & Ramaswamy, 2004a). Knowledge creation among peers also fosters usage intentions for the resulting service innovations (Kleijnen et al., 2009). However,

diverse patient needs, interests, and skills related to social interaction and knowledge creation require the careful coordination of activities.

The third component describes *actors* in the OHC. Although the authors' focus is on patient-centered communities, other actors may be active in the community too (Kuenne, Moeslein, & Bessant, 2013). Increasing the diversity of actors, by adding doctors and other healthcare stakeholders, might foster the exchange of diverse, rather than redundant, knowledge and increase learning opportunities (Dahlin, Weingart, & Hinds, 2005). However, diversity should be balanced with perceived similarity among actors, to increase common understanding of the community content and coordinate interactions (Ren, Kraut, & Kiesler, 2007).

The final component, *interdependencies* among actors and their activities, entails the conflict of trust versus privacy. Especially in a healthcare context, trust is required to put people at ease and allow them to share personal details (Bansal, Zahedi, & Gefen, 2010). Privacy issues, and especially the loss of control over health data, are central concerns for sharing healthcare information online (Bansal et al., 2010). However, this concern might be mitigated by coordinating trust-building mechanisms, such as self-disclosure. The extent to which a community member discloses personal information largely determines the level of trust created among community members (Ebner et al., 2009) and thus knowledge sharing and creation (Ridings et al., 2002). Furthermore, personal information reveals the level of similarity among members (i.e., homophily), which can foster collaboration among similar patients (McPherson, Smith-Lovin, & Cook, 2001).

2.3. Methodology

2.3.1. Overview

This research combines qualitative and quantitative approaches (Jick, 1979; Odekerken-Schröder et al., 2010). The authors start with a qualitative, in-depth analysis of online communities, then contrast these insights with existing literature and develop a coding scheme to differentiate among communities. By applying this coding scheme across relevant communities, the authors quantify their insights, detect similarities and differences, and map clusters of communities in a two-dimensional space. In the following paragraphs the authors provide an in-depth overview of the data analysis steps. Similar approaches have proven

helpful in studying heterogeneous patterns in complex research phenomena (Moeller, Ciuchita, Mahr, Odekerken-Schröder, & Fassnacht, 2013; Odekerken-Schröder et al., 2010).

2.3.2. Sample

With a comprehensive, systematic Internet search, via Google's and Yahoo's search engines (i.e., search terms: 'online health community', 'healthcare forum', 'cancer community', 'diabetes forum', etc.), together with expert consultations (i.e., physicians and business consultants), a sample of 63 English-language OHCs was constructed. Saturation was reached when similar set-ups (i.e., information sites with forums attached), topics (i.e., general communities versus specific communities) and objectives (i.e., informing patients) came back. The sample was reduced to 50 communities by selecting those with (1) public access (i.e., not restricted to a particular type of stakeholders, such as patients or doctors), (2) some degree of interaction (i.e., supported interactions among members), and (3) recent activities. In the sample, 21 communities focus on specific health topics, and the remaining 29 focus on health in general. An overview of the selected communities is provided in Appendix A.

Table 2-2 Data analysis phases and stages

Phase	Stage	Objective	Main techniques
Qualitative analysis	1	Develop a coding scheme	Categorization, abstraction, comparison, iteration
	2	Code 50 communities	Comparison, dimensionalisation, integration
	3	Interpretation of coding results	Integration, iteration
Quantitative analysis	4	Identify meta-categories for categorical principal component analysis and obtain object scores for a bidimensional representation of the coded communities	CATPCA
	5	Use the object scores obtained in Stage 4 to explore clustering possibilities	Hierarchical cluster analysis
	6	Determine the most appropriate cluster solution, analyze and interpret it	K-means cluster analysis

2.3.3. Data Analysis

In the analysis of the 50 communities, the authors undertook two three-stage processes (see Table 2-2). In the first phase, qualitative analysis techniques were used to develop a coding

scheme (Stage 1), code each community accordingly (Stage 2), and interpret the results (Stage 3). Then in the second phase, using quantitative analysis techniques, the authors performed a categorical principal components analysis (CATPCA) to obtain a bidimensional spatial representation of the coded communities (Stage 4), applied hierarchical cluster analysis to explore potential clustering possibilities in this space (Stage 5), and analyzed and interpreted cluster memberships for the most appropriate solution through k-means cluster analysis (Stage 6) (Moeller et al., 2013; Odekerken-Schröder et al., 2010).

Qualitative Analysis. In Stage 1 of the qualitative analysis, deductive (derive meta-categories from theory) and inductive (derive community components from data) strategies were combined to develop a coding scheme. To analyze the dataset of 50 online communities, the authors used a systematic approach as formulated by Corbin & Strauss (2015). In a first step, open coding is applied which means that the authors did not establish a coding scheme upfront, but rather let the codes emerge during the coding process. Online communities were defined as unit of analysis and labelled with relevant codes that reflected the research questions, thereby staying as close to the data as possible (Spiggle, 1994). Accordingly, the 50 communities were labelled as belonging to certain empirical categories (e.g., presence of community statistics). In doing so, the authors applied the fundamental, basic qualitative data manipulation operations defined by Spiggle (1994): categorization (classifying units of data) and comparison (exploring differences and similarities across incidents). In a second step, axial coding is applied which means that the concepts identified through open coding are related to each other through comparative analysis. Thereby the empirical categories (e.g., presence of community statistics) were combined into higher-order conceptual constructs (e.g., simple way of sharing information about the community) (Spiggle, 1994) through basic operations such as abstraction (creating higher-order conceptual constructs) and integration (of categories and constructs). In a third step, the community components, derived from data are combined with the meta-categories, deduced from theory. The four meta-categories from coordination theory appeared in the data set: (1) goals (cure and care), (2) activities (community situation, data transformation, data integration, and innovation intention), (3) actors (platform users), and (4) interdependencies (self-disclosure). During Stage 2, two independent coders reviewed the data set of 50 communities and resolved any differences through discussion. Intercoder reliability was calculated for each of the components by Krippendorff's Alpha (Goals: Cure: $\alpha=0.80$; Care: $\alpha=0.92$, Community situation: $\alpha=0.83$, Data transformation: $\alpha=0.90$, Data integration: $\alpha=0.90$, Innovation intention: $\alpha=0.83$,

Platform users: $\alpha=0.92$, Self-disclosure: $\alpha=0.96$) (Hayes & Krippendorff, 2007). In Stage 3, the categories and constructs were integrated and iteration was used to go back and forth between several research stages, to support induction and deduction (Spiggle, 1994).

Quantitative Analysis. For a more complete understanding of the dimensionality of OHCs, the qualitative phase was complemented with a quantitative phase (i.e., triangulation) (Denzin, 1970). In Stage 4, the authors conducted a special principal component analysis, known as CATPCA, which includes a nonlinear optimal scaling transformation of the meta-categories. Hence, complex, multivariate data can be analyzed that include nominal, ordinal, and numerical variables. In this way, CATPCA enabled us to capture the heterogeneous nature of OHCs. The authors imposed a two-dimensional solution on the data in order to obtain a parsimonious representation in the form of a bi-plot. The authors recoded the categories in the qualitative phase into categorical variables (Odekerken-Schröder et al., 2010), performed CATPCA, and obtained two dimensions, along with the object scores for each community on each dimension. Thereby, the object scores reflect how each of the 50 communities score on the two dimensions identified. Then in Stage 5, the authors conducted a hierarchical cluster analysis, using the standard squared Euclidian distance in combination with Ward's criterion. The object scores served as cluster variables. The authors checked multiple cluster solutions and decided—based on the output of the agglomeration schedule—that a four-cluster solution emerged as strongest on a conceptual level. This decision was based on (1) the even distribution of communities over clusters and (2) whether the communities bundled in clusters could be easily labelled in line with existing theory. In Stage 6, the authors conducted a four-means cluster analysis of the object scores of the CATPCA based on the iterate and classify method. Thereby four clusters of OHCs were identified, according to the two CATPCA dimensions. Crosstabs with a χ^2 test were constructed to support the description of the community clusters and bootstrapping was performed to confirm the robustness of the found 4-cluster solution.

2.4. Results

2.4.1. Qualitative Phase

During the qualitative analysis of the communities, the authors identified four meta-categories that reflect the components of coordination theory, in the context of OHCs (see Table 2-3).

Table 2-3 Coordination theory in online health communities

Meta-categories	Community components	Frequency
Goals	Cure	No: 2, Low: 6, Medium: 9, High: 33
	Care	No: 19, Low: 6, Medium: 12, High: 13
Activities	Community situation	No: 8, Simple: 16, Moderate: 16, Advanced: 10
	Data transformation	Low: 22, Medium: 21, High: 7
	Data integration	Anecdotal: 35, Structured: 8, Mixed: 7
	Innovation intention	No innovation: 30, Innovation: 20
Actors	Platform users	Patient: 34, Patient and experts: 9, patient and others: 7
Interdependencies	Self-disclosure	No: 18, Low: 17, Medium: 8, High: 7

The first component, goals, captures the cure- and care-related knowledge created in OHCs. By scanning the mission statements and community content, the focus of the community was identified as cure, care, or mixed, in terms of the value creation it intended to support. For example, the mission statement of *MDJunction.com* starts by noting that “group participation can offer emotional support, confidence and strength; can foster hope and can lead to improved coping”, suggesting that this community host aims for care value. However, the content in the community mainly pertains to cure, so the final coding was a mixed community, with medium levels of cure and care. That is, the mission statement provides an initial starting point, but community content was used to make the final judgment of the community’s goal. In OHCs, patients create cure-related value by providing information in their online profiles and sharing their experiences in online support forums, which offer a basis for discussion and new knowledge creation. Care-oriented value is provided as communication in online support forums, blogs, and chat rooms. Despite a lack of sociodemographic or visual cues, trusting, emotion-oriented relationships can develop in online contexts, though they might take longer (J. M. Wilson, Straus, & McEvily, 2006). The goals component was operationalized with two categorical variables, cure and care, which range from no to low to medium to high (Table 2-4). Two trained coders received the mission statement of the community together with a random selection of 50 online postings. A detailed description of the definitions of cure and care allowed them to assess the cure or care oriented goals of the OHC.

The second component, activities, relates to the community situation, data transformation, data integration, and innovation intentions. First, sharing updates about the community situation reveals information about the community and what content is currently thriving. For example, in *Germtrax.com*, the community host aggregates member data and provides it to

the community as graphs and reports regarding disease outbreaks (Germtrax, 2012). Different information sharing methods were categorized according to how much effort they demand from the community host, from no/low (e.g., sharing community statistics, highlighting popular content) to moderate (e.g., presenting word clouds and topic tags) to advanced (e.g., sharing discoveries based on member data) (Table 2-4). Second, data transformation occurs through tracking and health data visualization tools, forums, and blogs. For example, the data-driven *patientslikeme.com* community provides tools for patients to visualize their health data daily (PLM, 2013), which encourage them to reflect on their health situation and transform their existing knowledge in data that might be shared online. Several communities also were dedicated to collecting patients' reviews of products (e.g., drugs, vitamins, and supplements), doctors, or hospitals. These community tools aim to transform patients' existing knowledge, gained from their experiences with healthcare offerings, into online content that might be shared and spark new knowledge creation. This categorical variable was operationalized as low (i.e., one type of data transformation provided), medium (two or three types of data transformation), or high (four or five types of data transformation) (Table 2-4). Third, data integration refers to how different data sources get integrated into the community. Consider, for example, the patients' profiles on *patientslikeme.com*, which encourages them to update their health status with exact facts and numbers that then can be aggregated and shared with community members in the form of graphs and figures (PLM, 2013). In addition to this structured integration of patients' data, *patientslikeme.com* provides forums and opportunities to send personal messages, such that patients can discuss their disease in narratives, which allow for more rich and detailed content and discussions (PLM, 2013), in which patient data are mostly anecdotal. Data integration was coded categorically as structured (i.e., systematic graphs and figures), anecdotal (i.e., stories and narratives), or mixed (Table 2-4). Fourth, patients can be involved in different sequential stages of the innovation process, such as ideation, development, prototyping, and testing (Mascarenhas, Kesavan, & Bernacchi, 2004; Verma, Elg, Engström, Witell, & Poksinska, 2012). If patients are involved in the ideation stage, the community host formulates a predefined innovation challenge, and patients give their opinion and potential solutions. For example, in *innovationbyyou.com*, the host, which develops ostomy and incontinence appliances, probes patients' experiences with difficult-to-open packaging and potential solutions to make life easier (Innovation By You, 2013). Another approach lets patients formulate their own challenges. In *gemeinsamselten.de*, patients with rare diseases can formulate problems and present them to a variety of community members (Gemeinsamselten, 2013). In the

development phase, community members might discuss ideas in online forums to develop a concept from the initial idea, describing the technology, working principles, and form of the product or service. Once it reaches the prototyping phase, *innovationbyyou.com* involves members by providing them with toolkits to develop a mock-up of their optimal incontinence product (Innovation By You, 2013). The authors also find evidence of patient involvement in the testing phase of innovation, in the form of clinical trials. Patients who are active in OHCs are highly engaged and knowledgeable about their disease, easy to reach, and eager to participate in scientific activities. Innovation intention thus is operationalized as a dichotomous variable: no innovation intention versus innovation intention (see Table 2-4).

The third component, actors, consists of different participants who play an active role in the OHC. Although the authors focus on patient-centered communities, they also noted that several OHCs employ doctors to answer patient questions or act as moderators in online discussions. Several other healthcare stakeholders might play important roles or add specific knowledge, such as pharmaceutical companies, developers of medical devices, and research institutions. In the online community *patientopinion.org*, patients provide feedback about their experiences with healthcare services in U.K. hospitals. Their remarks get transferred to the hospital under review, and several stakeholders (e.g., nurses, specialists, administrative staff) respond by describing how the patient's feedback led to service improvements (Patient Opinion, 2013). This categorical variable was operationalized as only patients, patients and experts, or patients and other stakeholders (Table 2-4).

Finally, interdependencies capture the level of self-disclosure offered by the platform, not the personal choice of presentation by the patient. That is, this paper examines the characteristics of online communities, rather than the characteristics of its members. A low level of self-disclosure involves sociodemographic information (e.g., age, gender, location, picture), which has a limited impact on trust building. At the medium level, participants add general information about their disease (e.g., what type of disease, health interests). The highest level of self-disclosure means that participants add detailed information about their condition (e.g., treatment plans, drugs) (Table 2-4).

Table 2-4 Discretized variables in the categorical principal components analysis

Community components	Frequency (n=50)	Discretizing rule	
Community situation			
No community situation	8	No criteria	1. <i>No community situation</i>
Simple	16	Criteria 2-5	2. <i>Sharing community stats</i> 3. <i>Highlight top content</i> 4. <i>Highlight popular content/hot topics</i> 5. <i>Highlight recent topics</i>
Moderate	16	Criteria 6-9	6. <i>Word clouds (displaying topics)</i> 7. <i>Overview group members</i> 8. <i>Tagging</i> 9. <i>Top contributors</i>
Advanced	10	Criteria 10-11	10. <i>Presenting aggregated community data</i> 11. <i>Share discoveries based on member data</i>
Data transformation (DT)			
Low	22	Only 1 type of DT	Types of DT: <i>Discussion forum, Member blog, Chat, Q&A with peers, Personal Messages, Health tracking and sharing, Review tools, Data sharing & health geography, Polls & quick questions & surveys, Ask a doctor</i>
Medium	21	2 or 3 types of DT	
High	7	4 or 5 types of DT	
Data integration			
Anecdotal	35		
Structured	8		
Mixed	7		
Innovation intention			
No innovation intention	30	No innovation intention	
Innovation intention	20	Innovation intention:	<i>Idea sharing, reviews, share health data, health geography, clinical trials</i>
User			
Patients	34		
Patients and experts	9		
Patients and other stakeholders	7		
Self-disclosure			
No	18	No	
Low	17	Low:	<i>socio-demographic profile information (e.g. age, gender, location, picture)</i>
Medium	8	Medium:	<i>low profile information plus general information about their disease (e.g. type of disease, health interests)</i>
High	7	High:	<i>medium profile information plus more detailed information about his condition (e.g. treatment plans and drugs)</i>

2.4.2. CATPCA Dimensions: Knowledge Internalization and Knowledge Externalization

In Stage 1 of the analysis, four meta-categories were identified in the data set: (1) goals (cure and care), (2) activities (community situation, data transformation, data integration, innovation intention), (3) actors (platform users), and (4) interdependencies (self-disclosure). In Stage 4, only activities, actors, and interdependencies were considered to perform the CATPCA, because these meta-categories describe how goals get accomplished. Furthermore, because cure and care are the main knowledge outcomes of OHCs, they are explicitly linked to the resulting clusters from the CATPCA.

The authors computed ordinal variables related to the underlying categories (see Table 2-4). Two CATPCA dimensions resulted from these categories, so an object score was calculated for each community in the data set on each dimension. The first dimension retrieved from CATPCA comprises sharing the community situation, data integration, innovation intention, and user type, which is summarized under the heading *knowledge internalization*. The second dimension consists of data transformation and self-disclosure, which is labelled *knowledge externalization*. Both dimensions coincide with Nonaka's (1994) knowledge creation framework. They achieve eigenvalues greater than 1 and sufficient reliability for exploratory research (Cronbach's $\alpha=0.928$); they account for 73% of total variance (Table 2-5).

Knowledge internalization refers to tools that support people's learning by transforming their explicit knowledge into tacit knowledge (Nonaka, 1994); it integrates community situation, data integration, innovation intention, and user type. Sharing the community situation pertains to whether the community host explicitly shares information from within the community, such as community statistics, topic word clouds, or discoveries derived from member data. Communicating such information facilitates the internalization of knowledge created in the community by drawing attention to interesting content. Data integration involves the combination or integration of information sources held by different members, which then leads to more knowledge (Nonaka, 1994), whether in a structured or a more anecdotal way (Vicdan & Dholakia, 2013). Both routes stimulate knowledge internalization, though through different mechanisms. That is, structured data integration provides a clear overview of information and stimulates cognitive focus; anecdotal data integration instead supports cognitive processing through writing-as-thinking (Menary, 2007). An innovation intention implies the presence of tools that include patients in several innovation steps, ranging from

ideation to testing. These tools invite them to learn from one another and use their knowledge for innovation purposes (Swan, 2009), such that community members internalize the tacit knowledge of their peers. Finally, user type refers to who is using and internalizing the knowledge created in the community; patients alone, with experts (doctors, nurses, healthcare specialists), or with other healthcare stakeholders (pharmaceutical industry representatives, research institutions).

Knowledge externalization refers to tools that help members transform their tacit knowledge into explicit knowledge (Nonaka, 1994), which include data transformation and self-disclosure. Data transformation relates to individual interactions to externalize tacit knowledge so that others may use it as well (Nonaka, 1994). OHCs feature different tools to facilitate data transformations, such as discussion forums, health tracking, and short surveys to encourage knowledge externalization. The level of self-disclosure depends on the patient's online profile (Leimeister et al., 2005). More advanced profile possibilities (e.g., detailed disease information, treatment plans, and drugs) contribute more to knowledge externalization.

Table 2-5 CATPCA results

Categorical variable	Dimension 1	Dimension 2	Total
Community situation	0.839	0.245	
Data transformation	-0.271	0.869	
Data integration	0.862	0.097	
Innovation intention	0.819	-0.070	
User type	0.729	-0.082	
Self-disclosure	0.069	0.918	
Cronbach's alpha	0.760*	0.485*	0.928*
Total variance (eigenvalue)	2.728	1.680	4.408
Percentage of variance	45.473	27.993	73.466

Note: Total Cronbach's alpha is based on total eigenvalues. The values in the first six lines are the factor loadings. The bold values indicate that the variable was assigned to the respective dimension.

* Total Cronbach's alpha is based on total eigenvalues and indicative of the global fit of the CATPCA solution (Meulman, Van der Kooij, & Heiser, 2004). While the total Cronbach's alpha is assessed against typical thresholds (e.g., .70), the value of the Cronbach's alpha and eigenvalues per dimensions are only reported because they are instrumental to estimate the global fit of the total CATPCA solution.

2.4.3. Clusters

The fifth stage of the empirical analysis establishes the number of clusters. A four-cluster solution emerged as empirically balanced and conceptually strong. In the sixth stage, the authors established optimal cluster membership, such that each community was allocated to one of the four clusters. In Figure 2-1, the four-cluster solution that resulted from the average object score on each of the four meta-categories is presented (Table 2-6).

Table 2-6 Description of community clusters

	Cluster 1	Cluster 2	Cluster 3	Cluster 4
Number of communities	16	10	9	15
Community description	Basic information provider	Advanced patient knowledge aggregator	Systematic networked innovator	Uncomplicated idea sharer
Cure	High	High	High	High
Care	Medium/high	High	No	No
Community situation	Simple	Moderate	Advanced	No
Data transformation	Medium	High	Low	Low
Data integration	Anecdotal	Anecdotal	Structured	Anecdotal
Innovation intention	No	No	Yes	Yes
User type	Patient	Patient	Patient and other stakeholders	Patient
Self-disclosure	Low	Medium	Medium/high	No

Cluster 1 features simple sharing of information about the community situation, a medium level of data transformation, and anecdotal data integration. They tackle any conflicts about how to manage different activities by providing a basic level for each activity. Furthermore, they focus on one type of user, the patient, to increase common understanding of the community content. Similar backgrounds and mindsets facilitate their communication and may foster future participation in the community (McPherson et al., 2001). These communities support only a low level of self-disclosure, mostly focused on sociodemographic information. For example, *Inspire.com* provides online support for patients by allowing them to share their stories and experiences (Inspire, 2014). The authors refer to this cluster as *basic information providers*.

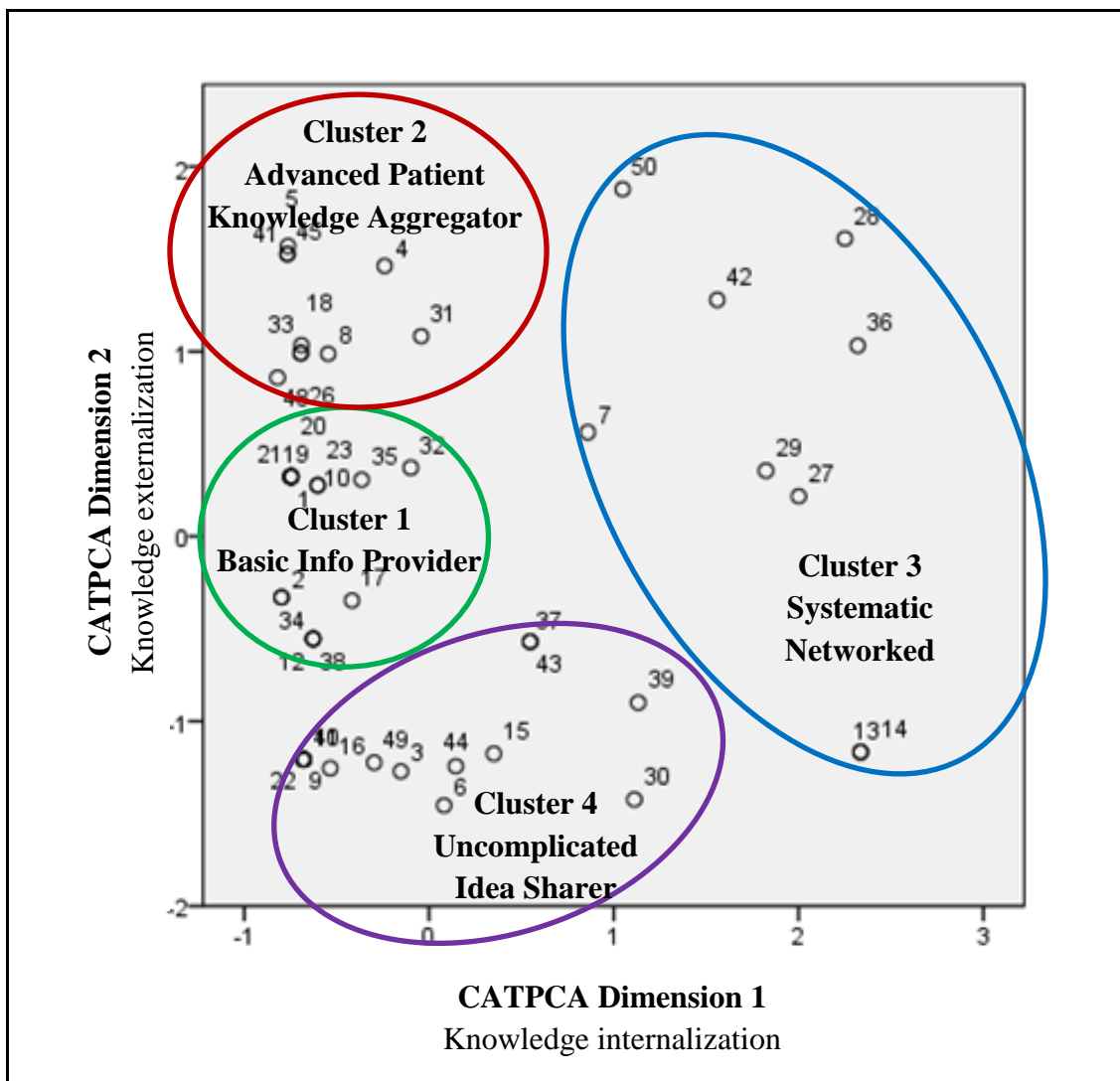
Cluster 2 exhibits moderate levels of sharing with regard to the community situation, combined with a high level of data transformation and anecdotal data integration. To manage their activities, these communities seek to provide tools to support data transformation.

Similar to Cluster 1, they focus solely on patients, but they offer a medium level of self-disclosure by adding general disease information to basic sociodemographic information. High cure and care value results, such as on *soberrecovery.com*, a platform that combines discussion forums, blogs, chat, and personal messages to aid people trying to overcome drug and alcohol addictions (SoberRecovery, 2014). This cluster consists of *advanced patient knowledge aggregators*.

The most prominent characteristic of Cluster 3 is its structured focus on innovation for patients and other stakeholders. The diversity of actors enriches community content by combining various opinions. They engage in advanced sharing of the community situation, but they provide relatively few tools for data transformation. These communities focus on satisfying patient needs by combining several activities at an advanced level. Furthermore, because of their search for innovation, they focus on both patients and other stakeholders, creating high value in terms of cure, but no value pertaining to care. The possibilities for self-disclosure are medium to high, because they add general and specific disease information in profiles. A prominent example is *patientslikeme.com*, where patients share their health data in a structured way (i.e., via an online profile) with peers and other stakeholders for innovation purposes (PLM, 2013). The authors refer to this cluster as *systematic networked innovators*.

Cluster 4 is dominated by anecdotal, patient-oriented innovation. A low level of sharing the community situation combines low data transformation and no self-disclosure. These communities mainly focus on innovation as their core activity, which facilitates their management. Because they target only patients, similarity in the community is high, which fosters participation. Similar to Cluster 1, these communities require only a low level of self-disclosure. They create high cure value, but no care value. The project of *patient-innovation.com* for example is a social network to facilitate sharing of innovative solutions to any disease, as developed by patients and caregivers (Patient Innovation, 2014). The patients and caregivers share stories of how they resolved the inconveniences of living with a certain pathology. The authors designate members of this cluster *uncomplicated idea sharers*.

Figure 2-1 Community clusters in the CATPCA dimensions biplot



2.4.4. Relationship of Clusters with Cure and Care

Because cure and care are central outcomes for OHCs (Chronister et al., 2006; Zainuddin et al., 2013), the authors investigate how different community configurations might relate to the nature of value creation: cure (i.e., exchanging comprehensible information, advice, guidance) and/or care (i.e., expressions of affection, listening and sharing concerns). First, all clusters exhibit a high level of cure-oriented value. The question of the synergistic or conflicting nature of cure- and care-related value thus can be answered by reaching a high level of cure, combined with varying levels of care. This finding seems logical, in that the main reason people go online is to find information, whereas social or affective relationships develop only over time (Saarni, 1999), when there is enough trust established between the participants. Providing cure-oriented value is a basic condition for attracting participants. Second, clusters

that focus on the community situation and data transformation and combinations provide medium to high levels of care. In these cases, the main reason to visit the community might be the need for cure, while care develops. Third, clusters that focus on innovation and idea sharing do not provide any care value. The main focus of these communities is engaging patients in the development of healthcare products and services, leaving little room for care.

2.5. Discussion and Research Implications

The authors conceptualize and empirically account for heterogeneity in OHCs by identifying four illustrative clusters that reflect the key components of coordination theory. From a theoretical perspective, this paper thus advances research in digital service provision by adopting a multidisciplinary approach. By combining coordination theory, as has been applied in various research disciplines with healthcare (Chronister et al., 2006), service (Vargo & Lusch, 2004b), and knowledge creation (Nonaka, 1994) literature, the authors provide a fine-grained picture of the components of OHCs. A healthcare provider perspective is adopted by shedding light on the relationship between cure- and care-related value propositions. Previous research has remained inconclusive regarding the synergistic or conflicting nature of these two dimensions (Apesoa-Varano et al., 2011; De Valck et al., 2001), but this research indicates that cure-related value might be a necessary condition for care-related value creation. Providing information thus offers a vital prerequisite for creating an OHC; care might be optional. Patients are drawn to online communities to find information, but over time, they could potentially develop a strong affective connection with their fellow participants and thus engage in the exchange of emotional information (Saarni, 1999). The authors explored this premise by gathering and analyzing additional data. A significant, positive correlation (Spearman's rho: 0.319, $p < 0.05$) between community age and the degree of care suggests that care might develop over time in online health communities.

The study's capturing of a dual value proposition advances research on coordination theory which has focused on cognitive (e.g. Edgington, Raghu, & Vinze, 2010; Janssen & Bodemer, 2013; Purohit et al., 2014), but omitted affective value. However, patients also seek care, or in other words affective value, from their healthcare services (Apesoa-Varano et al., 2011; De Valck et al., 2001). This is in line with existing services research that points towards the importance of cognitive and affective benefits delivered by the service provider (Dholakia et al., 2009). The findings highlight that activities related to data transformation such as wide presence of communication and visualization features to express members' experience

correspond with affective goals of the community. Intriguingly, affective goals seem less relevant when the community is aimed at supporting innovation.

Our findings demonstrate that communities can be categorized along two knowledge creation dimensions: knowledge externalization and knowledge internalization. These dimensions coincide with Nonaka's (1994) knowledge creation framework. Knowledge externalization relates to the extent to which a community provides tools to externalize the knowledge that members possess and transform tacit knowledge into explicit knowledge. For example, a community member who fills out a community profile externalizes knowledge about his individual situation. Using data transformation tools such as a discussion forum, he might communicate with others and transform his tacit knowledge into explicit knowledge, which then can be shared with other patients. Knowledge internalization instead focuses on who contributes knowledge and how this knowledge gets internalized and used, or the conversion from explicit to tacit knowledge. For example, updates about the community situation can aid patients in finding the right information at the right moment, such that it fosters knowledge internalization. The provision of innovation tools helps them probe other members' ideas and learning, so that these members can internalize others' knowledge. Finally, the user type describes the nature of the users who use community tools to internalize knowledge.

This study indicates that OHCs have the potential to satisfy unmet patient needs and support patient involvement during service delivery and medical decision making. However, these abilities might not always be favorable. Better informed patients likely demand more time during their patient–doctor encounters. Treating informed patients might be time efficient, in that they better understand their doctor's explanations, but they also might want to exhibit their knowledge or have additional questions (Fang et al., 2008). Better informed patients also might choose to follow their own beliefs, rather than those of their knowledgeable doctors, which undermines the doctor's authority and could have a strong detrimental effect on their health (Fang et al., 2008). Such potential negative effects of the OHCs and the empowered patients in general offer interesting avenues for future service research.

The current study contributes to several service research topics. First, the authors provide more insights into coordinating value co-creation in a collaborative context. By applying coordination theory, the authors shed light on the components of online health communities and their interaction. Second, this study supports the enhancement of the service experience. Rather than focusing on the service experience of the individual patient, the authors

investigate the role of patient communities and how to best develop and coordinate these communities that have positive outcomes for both patients and firms. Third, the authors demonstrate that online health communities are able to satisfy unmet patient needs, thereby contributing to transformative service research (Ostrom et al., 2015).

2.6. Managerial Implications

Most life science professionals acknowledge that their company is using or plans to use online social networks (Deloitte, 2014). However, to implement digital services successfully, value-based segmentation is required, so companies need a good understanding of what drives the value created by their services (McKinsey & Co., 2014). This research provides a clear segmentation for OHCs and specifies what activities need to be in place to create cure- and care-related value. In doing so, this paper reveals that coordination theory is a useful framework for managers to organize and manage activities in online communities. In turn, three management entities are distinguished that might benefit from this research: community managers, other stakeholders (e.g., healthcare organizations), and policy makers.

First, the framework proposed in this paper grants community managers a good overview of the activities that they might implement to achieve the community's goals. Because cognitive value enables affective value in OHCs, digital service providers should strongly encourage the exchange of factual information, advice, and guidance. Providing articles and blogs written by professionals may trigger discussions and shared treatment experiences among community members. When sufficient trust is established, affective relationships can develop, which in turn support the exchange of affective value. The community host also can foster affective value creation through anecdotal data integration and data transformation features. A moderator in online discussions can ask specific questions and probe participants' emotions, which should evoke affective value. Giving patients a place to tell their 'story' also increases knowledge among their peers about their background and previous experiences. In turn, it becomes easier for those peers to empathize with fellow participants and respond in an affective way. Hence, to successfully deliver digital services such as online communities, community managers should first focus on activities that foster cognitive value, followed by activities that stimulate affective value.

Second, other stakeholders (e.g., pharmaceutical companies, developers of medical devices, research institutions) can collaborate with existing online communities for research and

education purposes. But they should seek to tap communities whose activities align with the goals of the community (i.e., cure or care). A healthcare organization that is mainly interested in gathering factual information for service improvement should not probe Clusters 1 or 2, but rather focus on communities in Clusters 3 and 4, for example.

Third, policy makers should address the conflict between trust and privacy issues. This research indicates that three of four clusters use self-disclosure to support trust. In 1996, the United States passed the Health Insurance Portability and Accountability Act (HIPAA), which requires protections of patients' identity and personal health information (HHS, 2015). However, OHCs are not among the entities covered by HIPAA, so they can bypass its mandates (HHS, 2015). Further regulation is needed to keep up with these developments and ensure that online community managers use patients' data in an appropriate and ethical way (Kluge, 2000).

2.7. Limitations and Further Research

OHCs are an emerging phenomenon. Continued research should include emerging communities and conduct more extensive, quantitative analyses to validate these results. Furthermore, the authors deduced the value created in online communities from their mission statements and observations of community activities. Additional research might solicit the perceptions of community members through surveys too. This paper focused on patient-centered communities, with limited interference from professionals or other stakeholders, so it might be interesting to investigate professional-oriented communities. Previous research indicates that physician networks are characterized by overspending (Hammerschmidt, Falk, & Staat, 2012); online professional communities might help cut costs for end consumers and patients. Investigating how the key components of coordination theory emerge and how professional communities deal with their inherent conflicts could provide strong potential for improving resource utilization patterns. Furthermore, this paper focuses on the creation of cure- and care-related value as main goals of online health communities. However, other types of value might occur in these communities such as ethical, status and esteem value, as described by Holbrook (1999). Consequently, future research might look into these value types as goals of online health communities. Based on the data analysis (i.e. CATPCA) in this paper, the authors cannot state what community configuration is optimal to foster cure and care. Therefore, future research might apply Qualitative Comparative Analysis (QCA), developed by Ragin (2009) to determine the optimal community set-up. However, this was

beyond the scope of this paper. Finally, beyond either patients or their healthcare professionals, taking the perspective of the community host and investigating communities' business models might add more understanding of how different community configurations pertain to cure- and care-related value.

Chapter 3

Value Co-creation in Online Health Communities: The Impact of Patients' Reference Frames on Cure and Care ²

² An article based on this chapter is under review at *Psychology and Marketing*.

An earlier version of this chapter was presented at the 43rd European Marketing Academy Conference in Valencia, Spain.

3.1. Introduction

The digital nature of the twenty-first century economy provides consumers with access to a wealth of information and facilitates peer-to-peer interactions (Libai et al., 2010). Many industries, from consumer goods to healthcare, rely on peer-to-peer online communities as communication tools, co-creation platforms, or extensions to customer management systems (Alavi, Ahuja, & Medury, 2011; Blazevic & Lievens, 2008; Mahr & Lievens, 2012). For example, online peer-to-peer interactions can complement traditional, face-to-face healthcare encounters (Kivits, 2006); on the online health community *PatientsLikeMe.com*, members share information and emotional support through online postings that pertain to their shared disease. Connecting to peers through forums or private messages also enables these patients to tap into collective knowledge about new treatments and coping strategies, which helps them manage their disease and increases their adherence to treatment plans (Camacho et al., 2009).

Patients' reliance on online information to manage and understand their diseases has been accelerated by modern trends of increasing time constraints and rising healthcare costs, which force healthcare professionals to focus nearly exclusively on physical and medical treatments, rather than more complex patient needs (e.g., needs for empathy, comprehensible information, hands-on advice) (Johnson & Ambrose, 2006). Yet, patients seek both factual information about treatment (i.e., cure) and emotional support (i.e., care) (Apesoa-Varano et al., 2011; De Valck et al., 2001). By supporting patient-to-patient interactions online health communities (OHCs) can provide both cure- and care-related value. In these communities, patients simultaneously fulfil roles as providers and recipients of healthcare content that meets both informational and emotional needs (McColl-Kennedy et al., 2012). Despite recognition of this potential of OHCs, the healthcare industry has struggled with their implementation (McKinsey & Co., 2014), perhaps largely because healthcare customers are ill and under stress, demand high credence services, and require considerable attention, especially if they suffer from chronic diseases (Berry & Bendapudi, 2007).

To understand value creation in online communities, the current study examines mechanisms that steer patients' information processing, as manifested in their frame of reference (Reed, 2002). A patient enters a community with information about his individual situation, obtained from an encounter with a doctor, then shares this information as online postings about his own situation, or self-referencing (Silvia & Gendolla, 2001). The community context also encourages patients to focus on others and respond to their peers' postings though, such that

they contribute value by referring to others' situation, or other-referencing. The 'self' and 'other' referencing mechanisms accordingly refer to different types of information processing performed by the patient who posts messages in the online community (T. B. Rogers, Kuiper, & Kirker, 1977). Self-referencing reflects information processing guided by a traditional, offline healthcare model; other-referencing suggests information processing that is directed by an emerging online model (Duval & Wicklund, 1972). Both referencing types might co-exist in an online posting, if patients shift their attention between their own and others' situations. Therefore, the current research examines the impact of the reference frame of a patient's online posting on cure- and care-related value co-creation.

By investigating this topic, the authors address calls for more research into peer-to-peer sharing of information in online communities (Stokburger-Sauer & Wiertz, 2015) and increased understanding of value creation, especially for healthcare (Ostrom et al., 2015). This article makes three main contributions. First, it integrates services marketing theory (value co-creation) with social psychology (self versus other) (Duval & Wicklund, 1972) and thereby creates new insights about how information gets processed and then translated into cure- and care-related value. The reference frame a patient adopts (i.e., self versus other) in online postings emerges as a crucial determinant of his information processing mechanism and the nature of the value perceived by readers of the online posting. Second, this study adds to previous research on online communities by examining the effects of the community experience, capturing a potential temporal effect. Prior research on online communities has suggested some effects of experience on group cohesion (Ludwig et al., 2014) and performance (Postmes, Spears, & Lea, 1998); this study disentangles these effects, depending on the patient's reference frame. Third, the setting of this research introduces a new type of online data that provides healthcare researchers and practitioners with novel opportunities for understanding patient-to-patient interactions. Online communities offer a more naturalistic, unobtrusive way to gather sensitive information and thereby lead to more valid results (Kozinets, 2002). Specifically, this study captures the linguistic features of individual online postings to measure information processing, as influenced by online and offline encounters (Pennebaker, Mehl, & Niederhoffer, 2003). In turn, both academics and healthcare practitioners may gain insights into how patients (1) experience online community interactions, (2) process information from a self and/or other perspective, and (3) create cure- and care-related value.

The next section offers a review of literature into value co-creation in OHCs and some hypotheses regarding the impact of self- and other-referencing. After the description of the methodology, this article presents the study findings, and then concludes with a discussion and suggestions for further research.

3.2. Theoretical Framework: Value Co-creation in Online Health Communities

The concept of co-creation emphasizes the active role of customers in the creation of value (Prahalad & Ramaswamy, 2000). In healthcare contexts, value co-creation refers to “activities centered around the individual patient or in collaboration with members of the service delivery network including the patient, family, friends, other patients, health professionals and the outside community” (McColl-Kennedy et al., 2012, p. 6). Participation in a health community constitutes an additional activity, carried out by patients, that adds value to the central patient–provider interaction. The emergence of web-based information tools and social technologies (e.g., blogs, wikis, social networking services, social bookmarking, collaborative filtering, file sharing) has created increasing opportunities to communicate across the borders of time and space and to support the co-creation of knowledge sharing networks (Sawhney & Prandelli, 2000).

In a co-creation paradigm, customers are not passive recipients of products and services, but rather are active co-creators who integrate resources from diverse parties to create value (Prahalad & Ramaswamy, 2004b). Previous research into the impact of OHCs on offline behavior reveals their potential to foster collaboration and negotiation between patients and physicians (Keeling et al., 2015). The current research focuses instead on peer-to-peer communities, adopting a patient perspective, such that the focus is on value created by and for patients.

3.2.1. Co-Creation of Cure- and Care-related Value in Online Health Communities

According to social support research (Chronister et al., 2006; Cutrona & Russell, 1990; Mathwick et al., 2008; Nambisan, 2011), two generic types of value are created in OHCs: cure and care. Cure-related value refers to informational, cognitive content, defined by Cutrona and Rusell (1990, p. 322) as “guidance concerning possible solutions to a problem”. It has important implications, in that better informed and more knowledgeable patients are

more inclined to take an active role in their healthcare management and implement treatment plans (Camacho et al., 2009). These active patients want to be involved in the treatment decision-making process, so the chosen therapy likely fits the patient's treatment and outcome preferences better, which should enhance the general health status (Camacho et al., 2009). A patient from one of the largest multiple sclerosis patient communities illustrates a focus on cure with the following comment:

“I thought it would be helpful to condense some common question and answers about how to maintain blood pressure in one thread. This will grow over time and be a helpful resource. If you think of something that should be included... ask away!”

Care-related value co-creation instead refers to emotional, affective support, which Cutrona and Rusell (1990, p. 322) define as “providing/receiving comfort and security during times of stress”. Patients diagnosed with a life-threatening disease suffer high levels of psychological disturbance, anxiety, and stress, which demands emotional support (Ben-Sira, 1980). Peer-to-peer communities provide it in the form of empathy and affective support (Dholakia et al., 2009). Recognizing other patients' experiences and stories makes it easier to bear the burden of their disease and cope with psychological disturbances (White & Dorman, 2001). The following quote illustrates this care-related value, in a multiple-system atrophy (MSA) online community in which expressions of empathy are highly appreciated:

“That was a beautiful expression and truly helped me. I feel so affirmed and comforted. I feel the hug and the care, and from someone who knows what it is I am speaking about. You, too, are dealing with these things.”

To address both value dimensions, this study differentiates cure- and care-related value co-creation in patients' online postings. On the one hand, cure-related value aims to improve understanding of the disease and treatment; it appears as cognitive information in online postings. On the other hand, care-related value enhances feelings of belonging and empathy and appears as emotional information in online postings.

3.2.2. Value Co-creation through Self-referencing and Other-referencing

The co-creation of cure- and care-related value should depend on the reference frame, or information processing mechanism, used by patients when they post messages to the online community (Park, Shin, & Ju, 2015). Whereas a traditional healthcare model puts the

individual patient–doctor encounter at the center of attention, the rise of OHCs emphasizes the input of peers and collective healthcare delivery. Patients may have gathered offline in support groups in the past (Turner et al., 2001), but the online context provides access to a very large set of diverse peers, which increases the richness of the information exchange. The individual patient does not focus solely on the self anymore, but instead shifts attention between the self and peers. Therefore, this study adopts self-awareness theory from Duval and Wicklund (1972) to assess patients’ information processing in online communities. Awareness balances between the self and others, such that the ‘self’ implies awareness about internally generated information (e.g., perceptions, sensations, attitudes, intentions, emotions) with help from a healthcare professional, whereas ‘others’ indicates awareness about externally generated information that enables patients to benchmark their experience against the disease trajectories of their peers and direct their attention to the others in the group (Singer & Kolligian Jr, 1987). By focusing on peers, patients extend beyond their individual situation to develop a social frame of reference (Tajfel & Turner, 1985). In this sense, self- and other-referencing are complementary mechanisms that coexist in postings to online communities. A patient from one of the largest multiple sclerosis patient communities illustrates a self-referencing perspective with the following comment:

“I am noticing more autonomic symptoms. My entire life my temperature was always 98.6, until I was ill and I would get a fever. I am starting to wonder if my movement disorder is turning towards more of an autonomic struggle.”

Because patients are influenced by information retrieved from both traditional patient–provider relationships and patient-to-patient interactions, information processing occurs through self-referencing and through other-referencing. Hence, following quote illustrates the use of other-referencing by a patient in one of the largest neurobrain communities:

“All of your symptoms are Lyme disease symptoms. You must find a Lyme literate specialist and have them draw your blood and send it to IGeneX.”

In what follows, we develop and discuss the hypotheses regarding self- and other-referencing, which can be found in Figure 3-1.

Impact of Self-Referencing on Cure and Care. During doctor visits, patients probe their internally generated information, so the self is a natural reference for information processing.

Patients reflect on their individual treatment plan, their reactions to it, and their overall health status (Carver, 1979; T. B. Rogers et al., 1977). The knowledge gained from this internally directed attention triggers cognitive processes and insights (Gibbons et al., 1985; Kühnen & Oyserman, 2002), which translate into cure-based value. Hence, the information that patients discuss with their doctor is shared in the OHC via self-referencing. Therefore, a positive relationship should arise between self-referencing and cure-based value creation. Formally,

H1: *Self-referencing during participation in an online health community relates positively to cure-based value co-creation.*

Coping with chronic illness is an emotional journey, encompassing both negative (e.g., anxiety) and positive (e.g., hope) emotions (Pennebaker, Zech, & Rimé, 2001). A self-referencing perspective should increase the intensity of these emotional states (Mor & Winquist, 2002). However, patients often are reluctant to share their emotions with healthcare providers and strictly stay focused on physical or medical topics, because doctors rarely respond appropriately to expressions of feelings (P. M. Wilson, Kendall, & Brooks, 2007). When they participate in OHCs from a self-referencing perspective, patients do not create any emotional value in their online postings, which should lead to a negative relationship between self-referencing and the co-creation of care-based value. Accordingly,

H2: *Self-referencing during participation in an online health community relates negatively to care-based value co-creation.*

Impact of Other-Referencing on Cure and Care. When they engage in other-referencing, patients focus on other people's situation and contribute information (Duval & Wicklund, 1972). Even disease information they gain from a doctor visit may be shared, through other-referencing, as advice to peers in the community. That is, self-referencing produces content that is focused on venting or receiving advice, but other-referencing focuses on providing advice. Therefore, other-referencing encourages patients to make the shared content as interesting and relevant for others as possible, which also could induce information biases in online postings, due to misinterpretations of expert advice or ambiguous formulations (Hadlow & Pitts, 1991). Therefore, other-referencing may have a negative relationship with the co-creation of cure-based value. Formally,

H3: *Other-referencing during participation in an online health community relates negatively to cure-based value co-creation.*

Adopting an other-referencing perspective also means paying attention to other people's emotional aspirations and responding in an affective way by providing empathy (M. H. Davis, 1983; Hoffman, 1978). Because patients have experience coping with their disease, day in and day out, they are well suited to respond to emotional postings and provide care-based value to peers (Tyreman, 2005; P. M. Wilson et al., 2007). Furthermore, empathic concern is greater among people who share the same concerns or life-changing experiences, such as the diagnosis of a shared disease (Hodges, Kiel, Kramer, Veach, & Villanueva, 2010). A positive relationship then should arise between other-referencing and the co-creation of care-based value, such that:

H4: *Other-referencing during participation in an online health community relates positively to care-based value co-creation.*

Interaction with Community Experience. Patients' community experience (i.e., number of online postings they share) should capture possible temporal effects on information processing. The level of community experience balances the levels of self- and other-referencing and may alter the impacts on value co-creation. That is, when people's online community experience increases, they tend to conform with group norms, such that group cohesion gets stimulated (Postmes, Spears, & Lea, 2000). As previous research has shown, the collective knowledge created in online communities may be preferable to individual expertise, because communities combine many, diverse information sources (Surowiecki, 2005). However, group cohesion limits the amount of internal reflection among this group of diverse members, which also affects the nature of their online postings. Therefore, community experience should reduce the positive impact of self-referencing on care-based value co-creation:

H5: *The level of community experience attenuates the positive effect of self-referencing on care-based value co-creation.*

With regard to the predicted negative relationship between self-referencing and care-based value co-creation, due to patients' reluctance to share their emotions (P. M. Wilson et al., 2007), competence with sharing emotional content online should develop over time, depending on the social environment (Saarni, 1999). More experience with an online community and its members should make it easier to share emotional content based on internal reflection, or self-referencing (i.e., individual evaluations of feelings). That is, community experience should weaken the negative relationship between self-referencing and the co-creation of care-based value, such that:

H6: *The level of community experience weakens the negative effect of self-referencing on care-based value co-creation.*

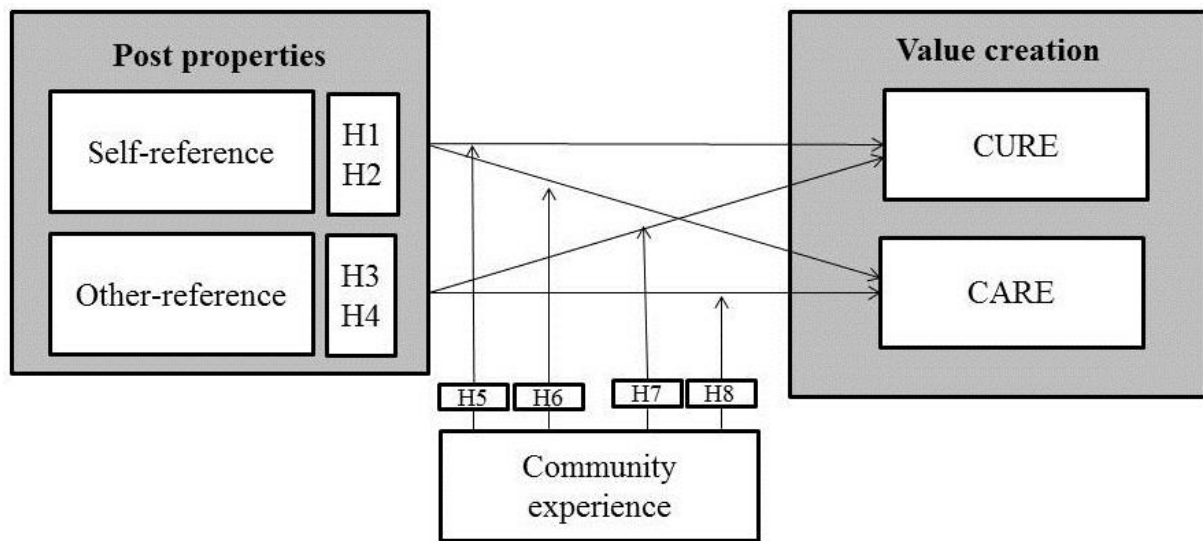
Other-referencing may have a negative effect on care-based value co-creation, due to potential biases linked to misinterpretations (Hadlow & Pitts, 1991; Reilly, 1989), and more community experience may create a greater barrier to constructive knowledge development within the community, due to members' conformity with group norms (Postmes et al., 2000). When patients provide advice to others, using other-referencing, they align their contributions with the existing community content. This trend undermines the value of collective knowledge co-creation (Lorenz, Rauhut, Schweitzer, & Helbing, 2011). Therefore, community experience may strengthen the negative impact of other-referencing on care-based value co-creation.

H7: *The level of community experience strengthens the negative effect of other-referencing on care-based value co-creation.*

Finally, the level of community experience should intensify the predicted positive influence of other-referencing on care-based value co-creation. The more active a patient is in the community, the more depth of knowledge he has about others' personal background, fears, pains, and insecurities (Cutler, 1995). These insights make it easier to provide care-related value. Furthermore, competences for sharing emotional content, as well as interpreting and responding to emotional content, develop over time (Saarni, 1999). More community experience then should strengthen the impact of other-referencing on care-based value co-creation. Formally,

H8: *The level of community experience strengthens the positive effect of other-referencing on care-based value co-creation.*

Figure 3-1 Conceptual framework



3.3. Methodology

3.3.1. Setting

The research data came from two OHCs, both part of one of the leading US healthcare platforms. The first community deals with general neurological and brain-related diseases (e.g., ALS, MSA, Parkinson’s, epilepsy). The second focuses on MSA, a neurodegenerative disorder characterized by a combination of Parkinsonian, autonomic, and cerebellar signs (Wenning, Colosimo, Geser, & Poewe, 2004).

With the exception of a few messages posted by community moderators, the authors retrieved all messages posted in two communities from their start until the researchers entered. The first community, Neurobrain, centered on neurological issues and provided 1292 online postings between September 2008 and October 2009. The second community, focused on MSA, provided 395 online postings between January 2011 and August 2012. The datasets did not reveal any significant differences in the outcome variables, so they were merged to increase the generalizability of the findings. The nature of the focal chronic diseases suggests that the healthcare consumers on these platforms have developed profound, tacit knowledge about their treatments and coping strategies, which makes these communities adequate research settings. Community members choose whether to start new threads or respond to previous threads; thus, researchers can review consumer communication as it takes place, without constraints or moderation. The authors gathered 319 discussion threads (204 from Neurobrain, 115 from MSA), with postings from 515 unique participants.

3.3.2. Operationalization

The data set of 1687 total postings was analyzed with a computerized text mining program, Linguistic Inquiry and Word Count (LIWC) (Ireland & Pennebaker, 2010; Niederhoffer & Pennebaker, 2002; Pennebaker, Francis, & Booth, 2001; Pennebaker & Ireland, 2011). This software analyzes text documents on a word-by-word basis by comparing the words in text files against an internal dictionary of 4500 words and word stems. Each word in the dictionary relates to one or more word categories. For example, the stem *aggress** is part of three word categories: Affect, Negative Emotion, and Anger. All words that comprise these first seven letters (e.g., aggression, aggressive, aggressor) increment these three subscales. Using relative measures circumvents any confounding effects from post length on our findings. For example, to obtain a measure for affect, the number of affective words in a posting would be divided by the total number of words in that posting. The validity of the LIWC program also has been confirmed in other online healthcare contexts, such as online self-presentation by anorexia patients (Lyons, Mehl, & Pennebaker, 2006) or the communication of positive emotions by cancer patients (Han et al., 2008).

Independent Variables: Self- and Other-Referencing. The *self-referencing* measure includes 12 first-person, singular pronoun categories (*I, my, mine*), counted in each online posting, divided by the total number of words in that post. *Other-referencing* reflects the use of 20 second-person, singular pronouns (*You, your, thou*), divided by the total number of words in the post. This method follows previous linguistic research related to a self-focus (D. Davis & Brock, 1975; Hung & Wyer Jr, 2011; Rude, Gortner, & Pennebaker, 2004; Tausczik & Pennebaker, 2010). Self- and other-referencing also can co-exist, and they may have a differential impact. Therefore, they are conceptualized as two separate continuous variables rather than a continuum, with self and other as two opposite extremes.

Dependent Variables: Cure and Care. The measures of the two dependent variables *cure* (i.e., factual information) and *care* (i.e., emotional support), relied on psychological measures. Cure entailed *cognitive and biological processes* that refer to practices such as *insights* (e.g., thinking), *body* (e.g., hand), and *health* (e.g., clinic) (Tausczik & Pennebaker, 2010). Hence, a measure for cure was calculated by counting the words related to cognitive and biological processes in a posting and by dividing this number by the total number of words in the online posting. The care measure included *affective and social processes* and *personal concerns* such as *religion* and *death*. Affective processes include two subdimensions: positive and negative

(Tausczik & Pennebaker, 2010). *Positive emotions* were gauged by the use of words such as *love, nice, and sweet*. *Negative emotions* instead were measured by the use of words such as *anger, anxiety, and sadness*. Social processes comprise three subdimensions: family, friends, and humans. *Family* is measured by the use of words such as *daughter, husband, and aunt*; *friends* is gauged by the use of words such as *buddy, friend, or neighbor*; and *humans* is measured by terms such as *adult, baby, and boy*. For the *religion* personal concerns, the measures focus on words such as *god, pray, or bless*, whereas the measure for *death* focuses on terms such as *fatal, dying, and coffin*. Hence, a measure for care was calculated by counting the words related to affective and social processes and personal concerns in a posting and by dividing this number by the total number of words in the online posting.

Moderating Variable: Community Experience. The measure of *community experience* is the number of postings, divided by membership length (days). This approach corrects for the likelihood that a longer-term member of the community naturally shares more postings.

Control Variables: Gender and Stars. Previous research suggests that *gender* plays a vital role in the nature of online communication (Boneva, Kraut, & Frohlich, 2001). Women are more inclined than men to send postings filled with personal content and use an expressive style that fosters emotional intimacy (Boneva et al., 2001). To control for this confounding effect, gender is a control variable in the model. Furthermore, patients can earn *stars* (i.e., 0 to 3), depending on how extensively they fill out their personal profile. The amount of personal information shared thus gives an indication of the patient's proficiency with processing individual information (i.e., self-referencing) and might affect the nature of value co-creation. Therefore, the number of stars is another control variable in the model.

3.3.3. Analytics

Seemingly unrelated regression (SUR), as implemented in STATA Release 9, served to test the hypotheses derived from the conceptual framework (Zellner, 1963). The descriptive statistics and correlations are in Tables 3-1 and 3-2. When the error terms of the regression equations in multiple equation systems are correlated, SUR provides more efficient estimates than does ordinary least squares. Breusch and Pagan's (1980) χ^2 test of independence confirms that the estimated disturbance terms correlated at a 5% significance level, with $\chi^2(1)=10.294$ and $p < 0.01$. The analysis is based on 1687 observations.

Table 3-1 Descriptive statistics

Independent variables	Self-referencing	M: 7.11	SD: 4.52
	Other-referencing	M: 2.09	SD: 3.41
Dependent variables	Cure	M: 8.24	SD: 5.10
	Care	M: 14.25	SD: 9.25
Moderating variable	Community experience	M: 0.98	SD:3.13
Control variables	Gender	Fem: 78.1%	Masc: 21.9%
	Stars	M: 1.46	SD: 0.99

Table 3-2 Correlation table

	Self-referencing	Other-referencing	Cure	Care	Community Experience
Self-referencing	1				
Other-referencing	-0.268**	1			
Cure	0.099**	-0.089**	1		
Care	-0.287**	0.499**	-0.228**	1	
Community experience	-0.028**	0.072**	-0.037**	0.010	1

Note: **Correlation is significant at the 0.01 level (two-tailed).

3.4. Results

Gender and profile stars represented the control variables in the SUR model and do not significantly ($\alpha=0.05$) affect the results. As the results in Table 3 reveal, self-referencing exhibited the expected positive effect on cure (H1, $b=0.211$, $\alpha=0.001$) and predicted negative effect on care (H2, $b=-0.084$, $\alpha=0.001$). For other-referencing, the results indicated a significant negative effect on cure (H3, $b=-0.062$, $\alpha=0.026$) and a significant positive effect on care (H4, $b=0.345$, $\alpha=0.001$). The interaction effect between self-referencing and community experience revealed the expected negative relationship with cure (H5, $b=-.011$, $\alpha=0.006$) and positive relationship with care (H6, $b=0.110$, $\alpha=0.001$). Regarding the interaction effect between other-referencing and community experience, the findings showed the expected positive effect on care (H8, $b=0.061$, $\alpha=0.040$), but no significant effects related to cure (H7, n.s.).

Table 3-3 Summary of results

	<i>Dependent Variables</i>	
	Cure	Care
Constant	1.687 (0.000)	2.47 (0.000)
<i>Independent variables</i>		
Self-referencing	H1 0.211 (0.000)***	H2 -0.084 (0.000)***
Other-referencing	H3 -0.062 (0.026)*	H4 0.345 (0.000)***
<i>Moderating variable</i>		
Community experience	0.192 (0.024)*	-0.329 (0.000)***
<i>Control variables</i>		
Gender	-0.025 (0.553)	0.024 (0.489)
Stars	0.011 (0.533)	0.024 (0.707)
<i>Moderation effects</i>		
Self-referencing × Community experience	H5 -0.101 (0.006)**	H6 0.110 (0.000)***
Other-referencing × Community experience	H7 -0.010 (0.784)	H8 0.061 (0.040)*

Note: Coefficients are reported, with standard errors in parentheses.

*** $p < 0.001$. ** $p < 0.01$. * $p < 0.05$.

3.5. Discussion and Research Implications

OHCs are an important source of value co-creation among peers (Nambisan & Nambisan, 2009; Weiss, Lurie, & MacInnis, 2008). The current study examines the impact of a patient's reference frame during online community participation on cure- and care-related value co-creation. In turn, it reveals that patients' self-referencing, associated with internal information processing, enhances cure-related value co-creation. Patients enter the OHC with a background based largely on a traditional patient–doctor encounter, during which the healthcare professional probes patients' symptoms as a basis for diagnosing and proposing a treatment plan (Silvia & Gendolla, 2001). This factual information prompts cure-related value co-creation. However, patients appear less inclined to engage in emotional support through self-referencing, because they focus on physical-medical issues in traditional models and thereby disregard emotions (P. M. Wilson et al., 2007). The self versus other perspective we adopt in this paper might be linked to the concepts of self- and social surveillance as used by Park, Shin & Ju (2015). The authors define self-surveillance as “behavior in which individuals monitor, manage, and control their own expression and presentation” while social surveillance is defined as “individuals' use of social networking sites to track others' actions, beliefs, and interests” (Park et al., 2015, p. 602). Self- and other surveillance are based on social cues and

affect how people adapt their behavior in a social appropriate way. In the current research context, however, we consider the self versus other perspective as an information processing mechanism that has an impact on the nature of the value created via online postings.

The finding that patients internally process information shared in a traditional patient–doctor encounter and share it online implies an important role for healthcare professionals in terms of sustaining and ensuring information quality. Moreover, this study demonstrates the important role of OHCs, in which other-referencing is another crucial information processing mechanism, beyond self-referencing. It stresses the crucial role of peers and other people’s experiences for value co-creation. Because patients are experts in coping with disease-related emotions and share the same life-changing experiences, they are well suited to provide peers with emotional support (Hodges et al., 2010). In this sense, other-referencing triggers an effect opposite to that of self-referencing: it stimulates the co-creation of emotional support (care-related value), but weakens cure-related value, likely due to the risk of misinterpretation when exchanging informational content with other laypeople (Hadlow & Pitts, 1991). That is, OHCs provide an excellent platform for providing care and support to patients, but a weaker role as platforms to enhance cure-related value. With this status, OHCs also represent opportunities for healthcare organizations to enhance the informational quality of patient-to-patient interactions. Information from patient–doctor encounters gets processed internally, then shared in the online community, so doctors must provide relevant, well-structured, easy-to-share information. Moreover, by observing patient-to-patient interactions in the online community, healthcare providers can learn about potential service improvements and innovations. The findings also show that both information processing mechanisms—self- and other-referencing—exist independently of each other and display unique, distinct impacts on value creation. In this sense, the online model complements traditional healthcare models involving only patient–doctor encounters.

To capture the potential temporal influence in information processing, this study identifies members’ community experience as an important moderator. When they engage in self-referencing, patients’ community experience enhances their group cohesion, which undermines cure-based value co-creation, because they reflect less internally. Yet, community experience also makes patients feel more at ease with regard to sharing emotional content, and it stimulates care-related value co-creation (Saarni, 1999). During other-referencing, community experience takes another route, facilitating the provision of emotional content and

thereby stimulating care-related value co-creation, because the patient gains better insights into the emotional state and background stories of his peers (Cutler, 1995).

This study indicates a major challenge for cure-related value co-creation. Although community experience seemingly should attenuate the impact of other-referencing on cure, no significant results arose, perhaps because patients have the potential to enhance cure-related value. The expertise that gradually develops through increased community experience might establish building blocks for more cure-related value co-creation. Then traditional healthcare providers may be pivotal for ensuring information quality, as well as play an active role in educating patients about how to share reliable cure-related information in OHCs.

Finally, this study applied text mining as an innovative approach to assess the focal variables. This method can capture the nature of the value co-creation (i.e., cure or care) in an unobtrusive way, which is especially important in emotionally challenging settings. Furthermore, patients are unaware of the reference frame they use during information processing, though they express this frame in the linguistic features contained in their online postings. This research affirms that text mining is an appropriate way to probe patients' unconscious information processing activities.

3.6. Managerial Implications

Despite the popularity of OHCs, many healthcare organizations struggle with implementing or coordinating such digital services (Bain & Co., 2012; Deloitte, 2010; McKinsey & Co., 2014). McKinsey & Company (2014) explicitly advises industry actors and policy makers to increase their understanding of what drives value in digital services. This research responds to that need in several ways. First, by investigating the patient experience in OHCs, this article highlights the patient's reference frame as an underlying information processing mechanism (Reed, 2002). The differential impacts of self- and other-referencing on value co-creation in OHCs suggest that online communities might be constructed as complementary services, beyond traditional patient–physician encounters. Healthcare professionals often are restricted in their time and budgets and cannot satisfactorily meet all patients' emotional support and additional information needs (Hoch & Ferguson, 2005; Johnson & Ambrose, 2006). But OHCs can help fulfil such needs and provide both cure- and care-related value. Therefore, healthcare professionals should consider ways to allocate patients to digital services to satisfy their unmet needs, cost effectively.

Second, patients internally process information from their encounters with their doctors, and then might share this information online. Although time constraints might prevent healthcare professionals from providing extensive information about a disease or treatment, they must ensure that each patient understands the information presented. In doing so, healthcare professionals can indirectly influence the quality of the information disseminated in the online community. For example, physicians might seek a more active role in briefing and informing their patients, in a structured and specific way, offering not only verbal clarifications, but also factual support in the form of brochures, digital references, self-management tools, and so forth. Patients should be more involved during such service encounters, which also might increase their satisfaction (Shaffer & Sherrell, 1997).

Third, this research investigates the impact of community experience on value co-creation: it weakens the relationship between patients' reference frames and cure, but strengthens the parallel relationship with care. Community managers therefore might try to decrease the impact of group cohesion by providing tools that stimulate contributions of content that deviate from the group norm. For example, through active moderation of discussions, managers might ask participants explicitly to "think outside the box" (Sibai, de Valck, Farrell, & Rudd, 2015). However, group cohesion should be strong enough to support trust building, as is needed to foster the co-creation of care. Tools that enable users to "tell their story" might encourage participants to get to know one another. Overall though, community managers face the challenging balance between encouraging group cohesion, to foster care, while mitigating excessive group cohesion, to facilitate cure.

Fourth, text mining can reveal patients' unconscious information processing activities and the nature of the resulting value creation. Healthcare organizations might benefit from using this technique as input for real-time monitoring of patients' well-being, which would enable them to explore unmet needs that might be fulfilled by new (online) services. Text mining also might contribute to the development of a community dashboard of key performance indicators, including standard measures, such as the number of new registrations and page views, as well as insights into the nature of the value created in the community (i.e., cure and care), tracked over time.

3.7. Limitations and Suggestions for Further Research

This study contains several limitations that may provide fruitful paths for research. First, the authors evaluated value co-creation on the basis of individual postings. A chronological order exists across online postings, so each post recapitulates, to some extent, the previous postings. Investigating the contribution dynamics within a discussion thread in depth is beyond the scope of the current research, though as an initial step, this study includes community experience as a dynamic construct. Further research along these lines might provide insights into how online value co-creation builds and develops over time. Investigators should examine different discussion threads, focusing on how the conversation develops through others' input, when the discussion ends, and why.

Second, no significant result emerged regarding the relationship between other-referencing and cure. A challenge for cure-related value co-creation thus is identified, implying a potential moderating role of expertise. More research is needed to validate the argument that expertise can fuel the potential for cure-related value among patients.

Third, in this study the authors operationalized cure and care as continuous variables by means of LIWC. However, future research might interpret the value dimensions as dichotomous variables in an online posting. Hence, cure and/or care are present, or not. This dichotomous operationalization might yield different results which should be examined in additional studies.

Fourth, the current study focuses on chronic illnesses (i.e. ALS, MSA, Parkinson's, epilepsy). Future research might include non-chronic conditions to investigate the impact of type of disease on self- and other-referencing and consequently on cure- and care-related value cocreation.

Finally, this study used LIWC, a standard computerized text analysis program, to measure the text-based variables associated with cure and care. The validity of the LIWC program has been confirmed in various online healthcare contexts (Han et al., 2008; Lyons et al., 2006), but more insights might be uncovered by applying text mining models that have been developed explicitly to measure cure- and care-related value in online communities. Additional studies should develop customized text mining models to probe the subdimensions of cure and care and thereby provide more fine-grained results related to the nature of online value co-creation in healthcare settings.

Chapter 4

Cure and Care in Online Health Communities: The Nature and Impact of Patients' Network Position³

³An earlier version of this chapter was presented at the 42nd European Marketing Academy Conference in Istanbul, Turkey.

4.1. Introduction

Patients increasingly use the Internet to gather health-related information and to connect with peers in online health communities (OHCs). Recent research on the US adult population indicates that 59% look online for health information, while 26% inform themselves online about other's experiences about health issues (Fox, 2011). Hence, peer-to-peer interactions in OHCs might be conceptualized as parallel online services that aid patients in maintaining their quality of life and thereby complement traditional face-to-face doctor encounters (Laing, Keeling, & Newholm, 2011). During these online interactions, patients co-create value which aids in coping with their condition (Apesoa-Varano et al., 2011). The value co-creation potential of a patient might depend on his structural position in the OHC which determines his access to knowledgeable and supportive peers (Kleijnen et al., 2009). Two types of value co-creation can be identified in the healthcare context. First, patients co-create cognitive or so called *cure*-related value which is cognitive information that helps them better understand their disease and learn about new treatments. Second, affective or so called *care*-related value conveys empathy to help patients in bearing the burden of the disease and coping with resulting stress (Apesoa-Varano et al., 2011). The distinction is reflected in the services literature where consumers extract cognitive and affective benefits from their relationship with the service providers, both in an offline (Beatty et al., 1996; Gwinner et al., 1998), and online setting (Dholakia et al., 2009; Mathwick et al., 2008). Despite the importance of cure and care in an online health context, no scale exists yet to capture online value co-creation. The current study addresses this measurement issue by developing and validating a scale for cure- and care-related value co-creation.

Peer provided cure- and care-related value has an impact on treatment adherence (Kim, Kaplowitz, & Johnston, 2004) which—given the high economic costs of non-adherence—raises interest for online communities in the healthcare industry (Camacho, 2011). A good illustration is the online community focused on the weigh-loss pill 'Alli' by GlaxoSmithKline (GSK). Since the drug is only effective in combination with a low-calorie and low-fat diet, GSK invited overweighted participants to share their personal experiences (Philips et al., 2010) and provide support in an online community in order to assure people of the efficacy of the medication (Ramaswamy & Gouillart, 2010).

We adopt a social network perspective to understand how value is being created in OHCs. According to Granovetter (1983) the way in which individuals are embedded in a structure of

social relationships influences their behavior. In our research context this would mean that the value co-creation potential of a patient depends on his structural position in the OHC. Hence, when a patient enters the OHC and starts interacting with peers via online postings, he builds meaningful relationships and becomes part of a network. Two structural network properties are assessed to capture a community member's network position: individual connectedness and individual integration (Kleijnen et al., 2009). Thereby connectedness refers to the number of people with whom a person interacts while integration reflects the degree to which members of an individual's network communicate with one another. Hence, an individual's level of integration in a network depends on his level of connectedness since an individual cannot be strongly integrated in a network without being connected to other network members. The patients' structural position within the network determines his access to information and consequently his potential to engage in cure- and/or care-related value co-creation. Therefore, social network analysis is a suitable way to acquire insights in how cure- and care-related value is being created in OHCs.

With this research, we aim for two contributions. First, we advance research regarding value co-creation in the context of healthcare services by developing and validating a scale that captures cognitive (i.e., cure) and affective (i.e., care) related value in OHCs. Cure and care are fundamental concepts in healthcare research (Apesoa-Varano et al., 2011; De Valck et al., 2001; Nambisan, 2011). However, the lack of an appropriate operationalization of cure and care hinders advancement in the study of value co-creation in OHCs. Previous research in OHCs merely categorizes community content without quantifying the nature of the value created (Loane & D'Alessandro, 2013a). This prevents future research to empirically investigate the link between the nature of online value co-creation and several health-related outcome variables such as stress, mental health, quality of life and patient adherence (Cohen & Wills, 1985; Kawachi & Berkman, 2001; Leung & Lee, 2005; Mo & Coulson, 2010). Therefore, this research aims to define and measure the items that community members use in assessing the level of cure- and care-related value co-creation. Second, in this study we apply a network perspective to examine the impact of a patient's network position on the nature of value co-creation in online postings. Previous research demonstrates that an individual's network position has an impact on value co-creation, but mainly focuses on cognitive value such as information distribution and knowledge sharing (Kleijnen et al., 2009; Reagans & McEvily, 2003). However, networks may also serve as a source of more affective oriented value co-creation which affects customers' attitudes (Loane & D'Alessandro, 2013b). Hereby,

an individual's connectedness and integration in the network might have a differential impact on cognitive (i.e., cure) versus affective (i.e., care) value co-creation. Therefore, this research aims to investigate the influence of an individual's network properties—connectedness and integration—on the potential to create cure- and care-related value.

Hence, we adopt a network perspective to understand how healthcare customers create cure- and care-related value in OHCs. Given the online context, netnography is used to collect and examine data from three OHCs and to determine the structural network properties of the community members. The paper is organized as follows. We start by reviewing the literature regarding value co-creation in OHCs and develop hypotheses regarding the impact of the network properties connectedness and integration. Next, we describe the research design and methodology thereby focusing on a scale development procedure as well as on the networks derived from the online communities. Finally, the findings are discussed followed by some major conclusions and suggestions for future research.

4.2. Literature Review

4.2.1. Value Co-creation in Online Health Communities

Value creation is at the heart of every company's competitive advantage and consequently of its survival in highly competitive markets. Recently, the meaning of value and the value creation processes shifted from a firm-centric towards a customer-centric view where unique value is created *with* the customer rather than created *for* the customer (Prahalad & Ramaswamy, 2004b). In this new co-creation paradigm, OHCs enable *collective* co-creation (O'Hern & Rindfleisch, 2010), indicating that connected patients can share their knowledge and experiences related to a disease or treatment, with the objective of providing support to peer consumers (Nambisan & Nambisan, 2009). Hereby, the interaction with other expert patients in a network fosters a collective support system that excels the information and skills of a single person. Thereby, an individual's structural position in the OHC is considered to drive value co-creation. Despite the importance of understanding and steering value co-creation, neither practitioners nor academics reached a consensus on a general understanding of 'value'. Depending on the adopted perspective (i.e., company versus customer) and orientation (i.e., product value versus relationship value), value is defined in a different sense (Lindgreen, Hingley, Grant, & Morgan, 2011). In the context of OHCs, we assess value as online support, or the outcome of cognitive (i.e., cure) and affective (i.e., care) oriented

activities displayed by healthcare customers. Thereby, the individual's structural network position is a vital driver of cure- and care-related value co-creation.

4.2.2. Value Co-creation in Healthcare: 'Cure' and 'Care'

Previous research identified two main value dimensions of online support; cure- and care-related value (Gustafson et al., 1999; Mo & Coulson, 2008; Nambisan, 2011; Rosenbaum & Massiah, 2007). Cure-related value consists of knowledge sharing activities and satisfies the cognitive need for information of patients. Patients can be considered as experts in living with their disease as they build up a considerable knowledge base over time. By sharing their knowledge and experiences, expert patients improve their peers' information competence and foster participation in medical decision making. Furthermore, they complement the cure provided by the healthcare professional with practical tips for living with a disease day in day out (Hoch & Ferguson, 2005). Care-related value consists of empathic activities and satisfies the affective needs of the patient. Hereby, peers share their emotions, provide expressions of empathy and enhance a feeling of belongingness which helps patients to control their anxiety and relieve distress and uncertainty (Dholakia et al., 2009). Furthermore, it complements care delivered by the professional, which may be expensive and time consuming (Nambisan, 2011).

4.2.3. A Social Network Perspective towards Value Co-creation

The way in which community members are embedded in their social network influences their access to information and consequently their cure- and care-related value co-creation (Granovetter, 1983). Therefore, social network analysis (SNA) is best suited to understand the ongoing value co-creation processes in healthcare related online communities. We follow the definition of social networks as introduced by Lea et al. (2006) "A social network is a set of people, organizations, or other social entities, connected by a set of socially meaningful relationships". In the current study two properties of an individual's position in a social network are examined; individual connectedness and integration. Specifically, individual connectedness is defined as the degree to which a person is linked to others within his network (E. M. Rogers & Kincaid, 1981, p. 178). In other words, individual connectedness represents the number of people with whom a person regularly interacts within the online community.

Cure-related value co-creation is determined by the extent to which one can connect to a large number of diversified knowledge sources. According to social network theory, this is determined by a person's position in his online social network and in particular their levels of individual connectedness and individual integration. A highly connected member has many interactions with a large number of network members (Lievens, de Ruyter, & Lemmink, 1999), hence we expect a positive relationship between connectedness and cognitive value co-creation. Since the information is more readily accessible, network members can acquire more cognitive value and consequently engage in cognitive oriented value co-creation. The level of individual integration reflects the degree to which members of an individual's personal communication network communicate with one another (E. M. Rogers & Kincaid, 1981, p. 178). Therefore, we hypothesize:

H1: Patients who are highly connected in their network contribute more in terms of cure.

A highly integrated member has a network with peers who intensively communicate with one another compared to members with a low level of individual integration (E. M. Rogers & Kincaid, 1981). Hence, individuals who are highly integrated in their network mainly retrieve cognitive value via the small group of people around them and have less access to distant parts of their social network (Granovetter, 1983). As a result the information exchange is more homogeneous in nature which leads to fewer new insights and has a detrimental effect on cognitive value. Hence, we expect that higher levels of integration have a negative impact on cure-related value co-creation. On the contrary, individuals who are poorly integrated enjoy a wide range of contacts and therefore are likely to obtain more non-redundant and diverse information (Granovetter, 1983). Hereby, the information exchange is more heterogeneous which fosters the creation of new, cognitive value. Hence, we expect that lower levels of integration have a positive impact on cure-related value co-creation. Consequently, we hypothesize:

H2: Patients who are highly integrated in their network contribute less in terms of cure.

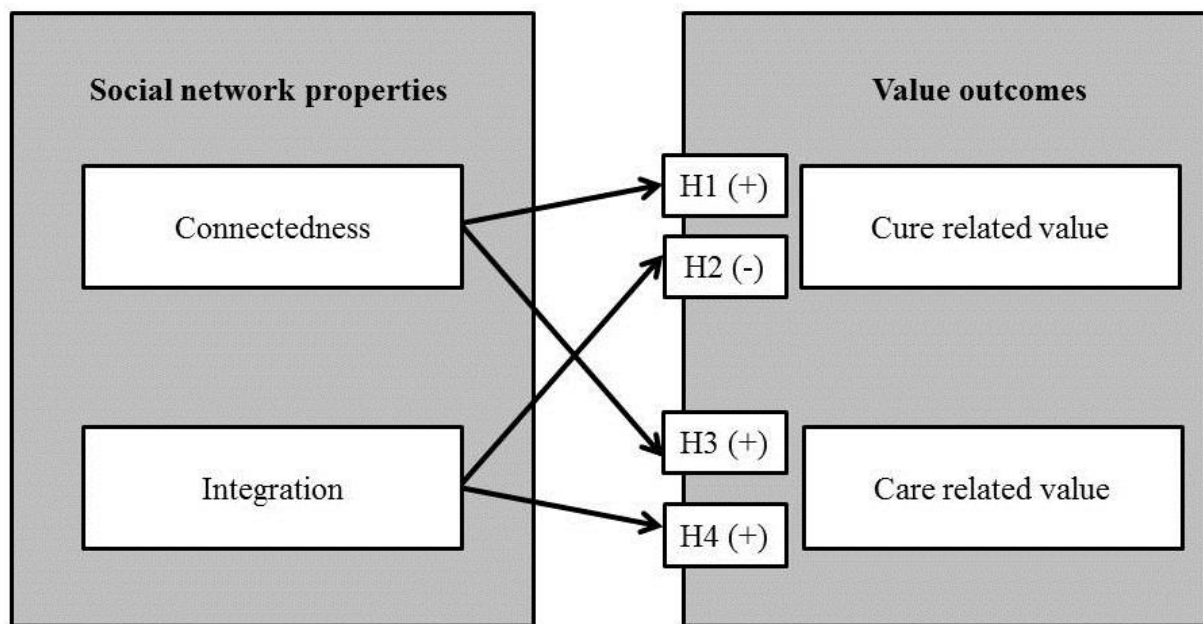
Care-related value co-creation is fostered by both highly connected and integrated patients. Larger networks tend to provide more affective support since there are more members available in the network who are willing and able to create care (Wellman, 1992). Hence, a highly connected member who communicates with a large number of network members (Lievens et al., 1999) is confronted with more care oriented postings than poorly connected

members and thereby more inclined to share his own emotions or provide empathy. Previous research claims that maintaining a large number of affective relationships involves responsibilities and mutual obligations, which might negatively influence the potential to create care-related value (Stokes, 1983). However, the technology used in OHCs aids members in maintaining a larger number of meaningful relationships than they can typically maintain without such technology. Hence, the technology allows members to briefly check updates and facilitate short verbal exchanges through asynchronous postings (Donath & Boyd, 2004). Therefore, we expect a positive relationship between connectedness and affective value co-creation. Hence, we hypothesize:

H3: *Patients who are highly connected in their network contribute more in terms of care.*

A very strongly integrated network enhances affective trust among its members which is defined as “genuine care and concern for the welfare of others” (Jayanti & Singh, 2010) and diminishes risk and uncertainty during social interactions (Coleman, 1988; McFadyen, Semadeni, & Cannella Jr, 2009). The trustful relationships that strongly integrated patients experience in the OHC foster them to communicate about taboo topics, intimate feelings and personal experiences (Jayanti & Singh, 2010; Leimeister et al., 2005). Furthermore, a highly integrated network facilitates the dissemination of sensitive, personal information which fosters the creation of affective value. Thereby, care-related value is co-created among the OHC members. Therefore, we expect a positive relationship between integration and affective value co-creation. We hypothesize:

H4: *Patients who are highly integrated in their network contribute more in terms of care.*

Figure 4-1 Overview of hypotheses

4.3. Methodology

4.3.1. Scale Development for Dependent Variables Cure and Care

4.3.1.1. Justification for Scale Development

Scant research regarding value co-creation in OHCs addresses their research questions with a qualitative approach (Loane & D'Alessandro, 2013b; Misra, Mukherjee, & Peterson, 2008). Thereby assumptions are made regarding the impact of online value on vital health outcomes. However to assess and demonstrate the impact of value co-creation on health outcomes such as physical and mental health, a scale for online value co-creation in OHCs needs to be developed and validated. By doing so, we address the call of the MSI on how to measure customers' perceptions of value (Marketing Science Institute, 2014). Thereby, we build on literature from social support since this concept contains dimensions that are similar to the cure and care value identified in the online health context. Table 4-1 provides an overview of existing social support scales. There is general consensus among researchers that social support is a broad, multidimensional construct with no single definition (Chronister et al., 2006). Thereby, two dimensions have been identified: structural and functional social support. For our scale development procedure, we build further on the functional dimension. The structural dimension is captured further in the paper by conceptualizing the independent variables (i.e., the patient's structural network position). The functional dimension includes

emotional, instrumental and informational support (Chronister et al., 2006). Hence, care-related value might be linked to informational support and care-related value to emotional support. Instrumental support such as tangible aid, financial and physical assistance was not relevant in the online context. The examination of existing scales for informational and emotional support revealed that they are not applicable in the online context. These scales are self-reported measures, hence they demand active participation and involvement of the patients who are active in the OHC. However, given the risk of response bias (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003) and the risk of intruding the trustful relationships that have been build online, we are convinced of the need to develop a reliable scale that can be applied to online postings in a non-obtrusive way.

Table 4-1 Literature overview social support

Authors	Scale/Coding scheme
Barrera et al. (1981)	The Inventory of Socially Supportive Behaviors (ISSB) is a 40-item scale on which respondents report the frequency with which they were recipients of supportive actions.
Broadhead et al. (1988)	The Duke-UNC Functional Social Support Questionnaire (Duke-UNC) consists of an 8-item, 2-scale, self-administered questionnaire and measures the structural and functional dimensions of social support.
Cohen et al. (1985)	The Interpersonal Support Evaluation List (ISEL) is a 40-item list of statements designed to measure the perceived availability of four separate domains of social support, as well as to provide an overall support measure.
Cutrona & Rusell (1990) Cutrona & Suhr (1992)	The Social Support Behavior Code (SSBC) is a coding scheme consisting of five dimensions that assesses social support between couples when one member of the couple discloses a personal problem to the other.
Kerres & Kilpatrick (2002)	The Child and Adolescent Social Support Scale (CASSS) consists of 40 items to measure a student's perceived social support from parents, teacher, classmates and close friends.
Norbeck et al. (1981)	The Norbeck Social Support Questionnaire (NSSQ) is an 11-item self-report measure that asks respondents to list significant people in their lives who provide social support.
Procidano (1983)	The Perceived Social Support measure from Friends and Family (PSS-Fr, PSS-Fa) consists of 20 items to capture the provision of emotional and information support by friends/family. Furthermore, the degree of support reciprocity is measured.
Sarason et al. (1983)	The Social Support Questionnaire (SSQ) contains 27 items, each of which requires a two-part answer: a list of the people who provide

	support in the specified circumstances, and a rating of satisfaction with that support.
Vaux et al. (1986)	The Social Support-Appraisals Scale (SS-A) is a 23-item instrument designed to evaluate the extent to which individuals believe that they are loved by, esteemed by, and involved with family, friends, and others.
Zimet et al. (1988)	The Multidimensional Scale of Perceived Social Support (MSPSS)* is a 12- item, Likert-scale (from 1='strongly disagree' to 7='strongly agree') measure. To capture the perceived adequacy of social support. *The multidimensional nature of this instrument does not lie in the number of dimensions measured, but from the measurement of three specific sources of perceived adequacy of support: family, friends, and significant others.

4.3.1.2. Scale Development Procedure

We rely on the accepted paradigm for scale development created by Churchill (1979) and later augmented by Hair et al. (2010), Netemeyer et al. (2003) and Nunnally & Bernstein (1994). Table 4-2 summarizes the scale development process that was used in this study.

Table 4-2 Scale development procedure

Stage	Objective	Procedure	Item reduction
Item generation	Generate a pool of items	<ul style="list-style-type: none"> • Literature review • In-depth interviews • Validate and classify items in an OHC context 	<ul style="list-style-type: none"> • 41 items (in-depth interviews) • 38 items (revision by moderators) • 16 items (validation in online context)
Final item selection and scale purification	<ul style="list-style-type: none"> • Final item selection • Scale purification 	<ul style="list-style-type: none"> • Gather a calibration sample (n=15) • Item analysis • Exploratory Factor Analysis • Confirmatory Factor Analysis 	<ul style="list-style-type: none"> • 15 items (item analysis) • 11 items (CFA)
Assessing construct validity	<ul style="list-style-type: none"> • Assess reliability • Assess unidimensionality • Assess convergent analysis • Assess discriminant analysis 	<ul style="list-style-type: none"> • Gather a confirmatory sample (n=78) • Confirmatory Factor Analysis 	

4.3.1.3. Theoretical foundation

We applied a qualitative approach to generate scale items. A literature analysis of existing informational and emotional support scales (see table 4-1) was performed. Despite the focus

of these scales on self-reported measures, we identified items that could be used as input for patient interviews.

4.3.1.4. Item Generation

We performed in-depth interviews with 10 patients (cancer n=7, stoma n=1, ALS n=2) who were member of an offline support group regarding a specific disease (for an overview of respondents: see Appendix B). Interviews lasted on average 71 minutes and probed into the topics of conversations in their support groups and how the patients perceived the value created during their gatherings. The interviews were recorded and transcribed. Two independent raters analyzed the transcripts and systematically identified and labeled dimensions of online value co-creation in OHCs. The findings were compared and differences resolved. A list of 41 items was generated from the in-depth interviews with patients. Additionally, 3 support group moderators were interviewed to check whether the list of online value co-creation items was complete and exhaustive, thereby assuring face and content validity (Hardesty & Bearden, 2004; Straub, Boudreau, & Gefen, 2004). Since the moderators pointed out some overlap between items, 3 items were combined. Hence, we proceeded with a final list of 38 items. Since these items were gathered in an offline context, we had to validate them in an online setting. Therefore, we asked 110 respondents who were members of an OHC to indicate whether they (1) recognized the items in the online context and (2) whether they would classify them as cure or care. Thereby, the items were placed in a random order. The sample consisted of 64% male and 46% female respondents. The average age was 34 years with a standard variation of 11 years. Through this quantitative pre-testing and validation in an online context the 38 initial items were reduced to 16 final items, from which 8 were classified as cure-oriented and 8 as care-oriented (see Appendix C for the classification task in the survey).

4.3.1.5. Final Item Selection and Scale Purification

The classification results then served as a starting point for the scale development process. Based on generally accepted purification guidelines, the initial pool of 16 items was refined (Churchill, 1979; Hair, 2010; Netemeyer et al., 2003). Thereby, a combination of statistical heuristics and content validity judgments was used (Rossiter, 2002). The respondents in this calibration sample (n=15) received an overview of the scale with an example for each item. Next, the respondents' understanding of the scale items was tested before they were asked to

assess 16 online postings based on the scale items (see Appendix D for the 16 online postings that were used as stimuli). Initially, a pool of 16 7-point Likert scale items was created, to measure two dimensions of online value co-creation (i.e., cure and care). Several control items were included to ensure that the respondents completed the survey with full attention and to eliminate response bias (Hensley, 1998). Furthermore, the items were placed in a random order so that items related to the same dimension were separated. At the beginning of the survey the respondents were asked about their Internet use to select participants with existing experience in OHCs. Finally, some demographic variables were measured (i.e., age, gender, location and level of education). A total of 15 participants in an online asthma community voluntarily filled in the survey and provided usable answers. Hence, we collected a dataset of 240 assessed postings. The sample consisted of 27% male and 73% female respondents. The average age was 37 years with a standard variation of 8 years.

Item analysis

First, we calculated the corrected item-to-total subscale correlations for each set of items, measuring the dimensions cure and care. Items with corrected item-to-total subscale correlations below 0.50 were considered for deletion (Novak, Hoffman, & Yung, 2000; Nunnally et al., 1994). After inspection, 1 item was deleted. Second, we calculated the correlations among items measuring the same dimension. Items with inter-item correlations smaller than 0.40 with similar traits were candidates for deletion. There were no items deleted during this phase. Finally, we examined correlations between items measuring different dimensions to assess problems regarding discriminant validity. Items that correlated more with items measuring the other dimension than with items measuring the same dimension were candidates for deletion. Also here, there was no need to delete any items. After these three item analysis steps, 1 item of the initial pools of 16 items was deleted, leaving 15 items for further refinement.

Exploratory Factor Analysis

Exploratory factor analysis (EFA) allows the researcher to explore the main dimensions to generate a theory, or model from a relatively large set of latent constructs often represented by a set of items (Hair, 2010). Thereby, Exploratory Factor Analysis using principal component analysis with oblique rotation was performed on the remaining 15 items. The KMO measure of sampling adequacy (0.787) and the Bartlett's test of sphericity ($\chi^2=1519.453$; $p<0.000$) suggested the data were appropriate for EFA. Four factors with Eigenvalues greater than one were extracted. The four dimensions together accounted for 66.89 percent of the total variance

in the EFA. Although we suspected a two-factor solution based on the literature, the results of the EFA suggest that cure and care each consist of two factors, hence four factors in total. The results of the EFA were then further used to purify the scale. Items that exhibited factor loadings below 0.40, cross-loadings above 0.40 and communalities below 0.50 were considered for deletion (Hair, 2010). After investigation, no items were deleted, leaving 15 items for further refinement.

Confirmatory Factor Analysis

Confirmatory factor analysis (CFA) offers the possibility to explicitly test a proposed factor structure against the sample data (Hair, 2010). In a first step, maximum likelihood estimation was used to test a 15-item, 4-factor model based on the exploratory factor analysis results. This initial analysis produced unacceptable fit indices ($\chi^2=420.946$; $\chi^2/df=5.011$; TLI=0.710; CFI=0.768; RMSEA=0.130; SRMR=0.117) (Hu & Bentler, 1999). The model was then refined by removing variables that contributed most to the lack of fit, based on the standardized residuals and modification indices. This stepwise process resulted in an 11-item, 4-dimensions confirmatory factor model with acceptable fit indices ($\chi^2=71.98$; $\chi^2/df=1.894$; TLI=0.945; CFI=0.962; RMSEA=0.061; SRMR=0.0478).

4.3.1.6. Assessing Construct Validity

We further assessed the validity of the refined 11-item value co-creation scale (see Table 4-3) by investigating unidimensionality, reliability, convergent validity and discriminant validity. In order to increase the reliability of our findings, a new and independent confirmatory sample was collected via an online survey. Similar to the respondents in the calibration sample, the respondents in this confirmatory sample received an overview of the scale with an example for each item. Then, they were asked to assess 16 online postings, based on the scale items. A total of 100 respondents filled in the survey, however, 22 cases were removed since the respondents did not take sufficient time to fill in the survey accurately. The final sample consisted of 78 respondents who assessed each 16 online postings. The sample consisted of 56% male and 44% female respondents. The average age was 33 years with a standard variation of 10 years. 71 % of respondents indicated that they visit their OHC more than once a month and 31% of respondents state that they at least post more than once a month in their OHC.

Unidimensionality and Reliability

We performed CFA on the new data to examine unidimensionality and reliability of the scale. The results supported the proposed 4-factor model with highly acceptable fit indices ($\chi^2=240.827$; $\chi^2/df=6.338$; TLI=0.962; CFI=0.974; RMSEA=0.065; SRMR=0.0348). Furthermore, a Cronbach's alpha of 0.823 for cure 1, 0.872 for cure 2, 0.827 for care 1 and 0.808 for care 2 in combination with composite reliabilities of 0.823 for cure 1, 0.858 for cure 2, 0.828 for care 1 and 0.825 for care 2 indicate that the measures are unidimensional and reliable (Nunnally et al., 1994). The average variance extracted estimates for cure 1 (0.608), cure 2 (0.751), care 1 (0.616), and care 2 (0.613) exceed the cut-off of 0.50 suggested by Bagozzi et al. (1988).

Convergent Validity

Convergent validity assesses the extent to which different measures that are designed to tap the same construct converge or share a high proportion of variance (Hair, 2010). Convergent validity was tested using the criterion that the loadings of all items hypothesized to measure the latent variable must be statistically significant (Hair, 2010). The critical ratios of all the items were significant at a 0.05 level (c.r. > 1.96, $p < 0.05$). Furthermore, all standardized factor loadings exceeded the cut-off of 0.50 which indicates good convergent validity.

Discriminant Validity

Discriminant validity assesses the extent to which a construct is truly distinct from other constructs (Hair, 2010). Discriminant validity was assessed by checking whether the confidence interval (\pm two standard errors) for each pair wise correlation estimate did not include the value 1.0 (Anderson & Gerbing, 1982). Both constructs (i.e., cure and care) satisfied this criterion. Table 4-5 also represents the correlation coefficients between each of the 6 dimensions in online value co-creation.

Table 4-3 Final scale and item measurement properties

Construct and item	Cronbach alpha	Composite reliability	Average variance extracted	Corrected item- to-total correlation	CFA item loading
Cure 1	0.823	0.823	0.608		
Information on diagnoses				0.635	0.780
Information on treatments and medication *				0.670	0.805
Information on causes				0.623	0.753
Cure 2	0.872	0.858	0.751		
Information on doctors and hospitals *				0.737	0.912
Information on external sources				0.679	0.848
Care 1	0.827	0.828	0.616		
Compliments				0.709	0.764
Prayer and blessing				0.683	0.785
Encouragement *				0.653	0.806
Care 2	0.808	0.825	0.613		
Empathy *				0.676	0.810
Sympathy				0.667	0.832
Feelings				0.594	0.672

* **Note:** These items are used in the remainder of the paper for application on the three datasets.

4.3.1.7. Nomological validity

As a consequence of the psychometric procedure for scale development, the insight arose that each value dimension consists of two distinct components. Hence, we split our dependent variables ‘Cure’ and ‘Care’ in the following way:

Table 4-4 Splitting of the dependent variables

Former dimension	Adapted dimension
H1: Connectedness → Cure	H1a: Cure 1 (Information on treatments and medication) H1b: Cure 2 (Information on doctors and hospitals)
H2: Integration → Cure	H2a: Cure 1 (Information on treatments and medication) H2b: Cure 2 (Information on doctors and hospitals)
H3: Connectedness → Care	H3a: Care 1 (Encouragement) H3b: Care 2 (Empathy)
H4: Integration → Care	H4a: Care 1 (Encouragement) H4b: Care 2 (Empathy)

Table 4-5 Correlation coefficients between 6 dimensions of online value co-creation in OHCs

	Dia	T&M	Cau	D&H	Ext	Com	P&B	Enc	Emp	Sym	Fee
Information on diagnoses (Dia)	1	0.629 0.000	0.601 0.000	0.564 0.000	0.561 0.000	0.455 0.000	0.379 0.000	0.339 0.000	0.403 0.000	0.373 0.000	0.389 0.000
Information on treatments and medication (T&M)	0.629 0.000	1	0.593 0.000	0.616 0.000	0.569 0.000	0.509 0.000	0.422 0.000	0.374 0.000	0.416 0.000	0.406 0.000	0.395 0.000
Information on causes (Cau)	0.601 0.000	0.593 0.000	1	0.577 0.000	0.507 0.000	0.462 0.000	0.396 0.000	0.316 0.000	0.432 0.000	0.360 0.000	0.364 0.000
Information on doctors and hospitals (D&H)	0.564 0.000	0.616 0.000	0.577 0.000	1	0.773 0.000	0.560 0.000	0.495 0.000	0.461 0.000	0.486 0.000	0.458 0.000	0.385 0.000
Information on external sources (Ext)	0.561 0.000	0.569 0.000	0.507 0.000	0.773 0.000	1	0.521 0.000	0.447 0.000	0.447 0.000	0.436 0.000	0.400 0.000	0.328 0.000
Compliments (Com)	0.455 0.000	0.509 0.000	0.462 0.000	0.560 0.000	0.521 0.000	1	0.615 0.000	0.580 0.000	0.478 0.000	0.499 0.000	0.502 0.000
Prayer and blessing (P&B)	0.379 0.000	0.422 0.000	0.396 0.000	0.495 0.000	0.447 0.000	0.615 0.000	1	0.648 0.000	0.550 0.000	0.577 0.000	0.472 0.000
Encouragement (Enc)	0.339 0.000	0.374 0.000	0.316 0.000	0.461 0.000	0.447 0.000	0.580 0.000	0.648 0.000	1	0.538 0.000	0.595 0.000	0.505 0.000
Empathy (Emp)	0.403 0.000	0.416 0.000	0.432 0.000	0.486 0.000	0.436 0.000	0.478 0.000	0.550 0.000	0.538 0.000	1	0.696 0.000	0.522 0.000
Sympathy (Sym)	0.373 0.000	0.406 0.000	0.360 0.000	0.458 0.000	0.400 0.000	0.499 0.000	0.577 0.000	0.595 0.000	0.696 0.000	1	0.538 0.000
Feelings (Fee)	0.389 0.000	0.395 0.000	0.364 0.000	0.385 0.000	0.328 0.000	0.502 0.000	0.472 0.000	0.505 0.000	0.522 0.000	0.538 0.000	1

Note: Pearson correlation coefficients are shown with 2-tailed significance levels.

4.3.2. Netnography

To answer our research question, data was gathered through means of netnography in three OHCs that are part of one of the leading healthcare platforms in the US. Netnography provides an unobtrusive way to study consumers online (Kozinets, 2002). Thereby, researchers use publicly available information from online communities to understand consumer behavior. Kozinets (2002) defines the concept as “a new qualitative research methodology that adapts ethnographic research techniques to the study of cultures and communities emerging through computer-mediated communications”. Our approach to data gathering and analysis can be seen as partial netnography since we observe community content, but do not actively participate in online conversations (Kozinets, 2010; Loane & D’Alessandro, 2013b). The first community under study deals with general neurological and brain related diseases (e.g., ALS, MSA, Parkinson, Epilepsy). Hence, we refer to this community as ‘Neurobrain’. The second community focuses on MSA (i.e., Multiple System Atrophy) which is a neurodegenerative disorder characterized by a combination of Parkinsonian, autonomic and cerebellar signs (Wenning et al., 2004). The third community concentrates on Epilepsy, which is a group of related disorders characterized by a tendency for recurrent seizures (Penfield & Jasper, 1954). To assure that we defined the correct network boundaries, all online postings since the start of the communities until the entrance of the researchers were captured (S. S. Smith, 2014).

Table 4-6 provides a descriptive overview of the three communities which were selected based on their diversity in terms of topic, i.e., Neurobrain is a general community while MSA and Epilepsy are targeted at a specific condition. Furthermore, the two specific datasets differ in terms of their structure, i.e., the MSA community contains a high number of short threads, while the Epilepsy community contains a low number of long threads. The differences between communities might impact the patient’s online participation and consequently his value co-creation. Hence, by investigating three communities instead of one, we are able to investigate the value co-creation in OHCs in more depth and validate our findings.

Table 4-6 Descriptive overview of three datasets

Dataset	Members	Postings	Threads	Postings per thread	Postings per member	Min postings per member	Max postings per member
MSA	113	510	91	4.91	4.51	1	52

Epilepsy	134	515	45	11.44	3.84	1	50
Neurobrain	220	509	63	7.95	2.31	1	48

4.3.3. Scale Application on Three Datasets

Since the application of an 11-item scale on more than 1500 online postings might introduce method bias in the complex context of OHCs (Podsakoff, MacKenzie, & Podsakoff, 2012), we reduced the scale and retained the four items with the highest factor loading, i.e., ‘Information on treatments and medication’ for Cure 1, ‘Information on doctors and hospitals’ for Cure 2, ‘Encouragement’ for Care 1 and ‘Empathy’ for Care 2. This approach is in line with extant research that calls for single-item measures in order to reduce the cost of research and the burden on the users of a scale (Bergkvist & Rossiter, 2007; Drolet & Morrison, 2001; Rossiter, 2002).

After coding all online postings of each community member on the four value dimensions (Mahr & Lievens, 2012) via a 7-point Likert scale (1: strongly disagree that this message contains the following value dimension, 7: strongly agree that this message contains the following value dimension), we aggregated them to obtain a total score for Cure 1, Cure 2, Care 1 and Care 2 on an individual level. Intercoder reliability was calculated for each value dimension by Krippendorff’s Alpha (Cure 1: $\alpha=0.82$; Cure 2: $\alpha=0.79$, Care 1: $\alpha=0.86$, Care 2: $\alpha=0.91$) (Hayes & Krippendorff, 2007). Thereby, a weighted average was calculated, taking into account the number of postings by the individual and the maximum number of postings per community member.

4.3.4. Network Measures for Independent Variables Connectedness and Integration

Ucinet VI, the statistical package for social network analysis was used to extract the network measures (Borgatti, Everett, & Freeman, 2002). Thereby, we focus on the individual community member, (i.e., actor) as unit of analysis. By means of netnography we constructed for each health community a valued, undirected communication matrix based on the number of online postings to which two actors are simultaneously exposed. Since online communities consist of threads which are discussions focused on a particular topic, we consider two actors to be linked when they are active in the same thread. However, some actors may be exposed to a short thread of only five postings, while others are linked through a long discussion of 20 postings. Therefore, we use the number of online postings to which two actors are simultaneously exposed as values for the communication matrix. For example, a frequency of

five in the communication matrix (i.e., $f_{ij}=5$), means that actor i is exposed to the same five messages as actor j , across several threads. Based on the frequencies, we constructed one communication matrix for each of the three communities. Next, these matrices were dichotomized to use as input in Ucinet VI to calculate connectedness and integration. The cut-off rates to dichotomize the communication matrices were based on several criteria such as the communication patterns and participation level (Lievens et al., 1999). The combination of these criteria led to a cut-off rate of 5 online postings to which two actors are simultaneously exposed for MSA, 11 for Epilepsy and 8 for Neurobrain. To calculate connectedness (C) and integration (I) for each actor i in the network, Ucinet retrieved his personal communication matrix (d_i) from the dichotomized communication matrix. Thereby, individual connectedness is calculated by the number of non-zero entries for actor i in his row or column entry (Scott, 2007), expressed by following formula:

$$C_i = \sum_i d_{ij}$$

Individual integration, then, is calculated by dividing the existing links in actor i 's personal network (d_i) by the total number of possible links in that same network. Hereby the size of the individual network of actor i is presented as n_i (Kleijnen et al., 2009). This is expressed in following formula:

$$I_i = \frac{\sum_j [d_{ij}(\sum_k d_{jk})]}{n_i(n_i - 1)/2}$$

After retrieving the levels of connectedness and integration for every actor in each of our three networks, the data was exported to SPSS for further analysis in combination with the value constructs.

4.3.5. Data Analysis

Given extreme skewness of the data (see Table 4-7), which could not be solved by transformation as suggested by Hair (2010), crosstabs were used to provide an answer to the hypotheses formulated (Janssens, Wijnen, De Pelsmacker, & Van Kenhove, 2008) (see Appendix E). The dependent and independent variables were dichotomized based on their median (i.e., median split), which is a common technique in marketing research (Barone, Norman, & Miyazaki, 2007). Since the median is equal to the maximum value of integration in the Neurobrain dataset, the cut-off value of 99 is used to create two groups that are comparable in size. Notwithstanding the critiques on median split (Irwin & McClelland,

2003; Knüppel & Hermsen, 2010), we believe it is the most appropriate solution due to the extreme skewness of the data.

Table 4-7 Descriptive overview dependent and independent variables

		Min	Max	Mean	Std Dev	Median	Skewness	Kurtosis
MSA	Cure 1	1.02	7.42	3.31	2.39	2.69	0.522	-1.29
	Cure 2	1.02	7.13	1.61	1.31	1.04	2.875	8.38
	Care 1	1.02	7.13	1.24	0.71	1.04	5.868	43.58
	Care 2	1.02	7.13	1.44	0.99	1.04	3.11	11.13
	Connectedness	0.00	52.00	8.39	9.93	5.00	2.24	5.49
	Integration	0.00	100.00	70.82	34.47	85.90	-0.831	-0.65
Epilepsy	Cure 1	1.02	7.63	3.79	2.28	4.01	0.077	-1.38
	Cure 2	1.02	7.14	1.37	1.02	1.03	4.13	18.44
	Care 1	1.02	7.14	1.61	1.31	1.04	2.55	6.02
	Care 2	1.02	8.68	1.40	1.14	1.04	4.09	18.16
	Connectedness	0.00	78.00	14.25	13.46	11.00	2.63	8.20
	Integration	0.00	100.00	81.20	25.79	98.99	-1.12	0.08
Neurobrain	Cure 1	1.02	7.88	4.29	2.58	4.17	-0.14	-1.63
	Cure 2	1.02	7.15	1.27	0.88	1.03	4.57	23.05
	Care 1	1.02	6.13	1.30	0.94	1.03	3.90	14.53
	Care 2	1.02	7.15	1.76	1.63	1.03	2.19	3.56
	Connectedness	0.00	72.00	9.83	8.99	8.00	3.77	20.71
	Integration	0.00	100.00	85.65	23.70	100.00	-1.59	1.64

4.4. Results

The scale development procedure revealed a 4-factor structure for cure and care value in OHCs: Cure consists of Cure 1 (i.e., Information on treatment and medication) and Cure 2 (i.e., Information on doctors and hospitals). Care consists of Care 1 (i.e., Encouragement) and Care 2 (i.e., Empathy). Hence, we examine the impact of connectedness and integration on Cure 1, Cure 2, Care 1 and Care 2. The results are shown in Table 4-8. Connectedness does not exhibit the expected positive effect on Cure 1 (i.e., H1a), we find non-significant results in the MSA and Epilepsy community and a significant negative effect in the Neurobrain community. The hypothesized positive effect of connectedness on Cure 2 (i.e., H1b) is confirmed in all three communities. Integration does not exhibit the expected positive effect on Cure 1 (i.e., H2a), hence we find non-significant results in all three communities (i.e.,

H2a). The negative effect of integration on Cure 2, however, is confirmed in all three datasets (i.e., H2b). Connectedness exhibits the expected positive impact on Care 1 and Care 2 in all three communities (i.e., H3a and H3b). However, as opposed to our expectations, we find a significant negative effect of integration on Care 1 and Care 2 in all three datasets (i.e., H4a and H4b).

Table 4-8 Summary of results

		Dependent Variables			
		Cure 1	Cure 2	Care 1	Care 2
Independent variables	Connectedness	H1a MSA: n.s. Epilepsy: n.s. Neurobrain: neg*	H1b MSA: pos* Epilepsy: pos* Neurobrain: pos*	H3a MSA: pos* Epilepsy: pos* Neurobrain: pos*	H3b MSA: pos* Epilepsy: pos* Neurobrain: pos*
	Integration	H2a MSA: n.s. Epilepsy: n.s. Neurobrain: n.s.	H2b MSA: neg* Epilepsy: neg* Neurobrain: neg*	H4a MSA: neg* Epilepsy: neg* Neurobrain: neg*	H4b MSA: neg* Epilepsy: neg* Neurobrain: neg*

Note: pos* represents a significant positive relationship based on crosstabs analysis combined with χ^2
 neg* represents a significant negative relationship based on crosstabs analysis combined with χ^2
 n.s. represents a non-significant relationship

4.5. Discussion and Research Implications

OHCs are an important source of value co-creation between peers (Nambisan & Nambisan, 2009; Weiss et al., 2008). The current study examines the impact of a patient’s structural network position (i.e., connectedness and integration) on cure- and care-related value co-creation. In doing so, a scale was developed to measure cure- and care-related value co-creation. The psychometric procedure revealed that each value dimension consists of two components. Hence, ‘Cure’ consists of *Information on treatment and medication* and *Information on doctors and hospitals* while ‘Care’ consists of *Encouragement* and *Empathy*. This splitting of cure and care is in line with extant social support research which emphasizes the multidimensional nature of the construct (Cutrona & Russell, 1990). Developing this scale might advance future research regarding value co-creation in OHCs since this allows empirical testing of the impact of cure and care on important health outcomes (Cohen & Wills, 1985; Kawachi & Berkman, 2001; Leung & Lee, 2005; Mo & Coulson, 2010).

This study indicates that a patient's connectedness enhances cure-related value co-creation while the level of integration diminishes the potential for creating cure-related value. However, this finding was only supported for Cure 2 which covers information on doctors and hospitals. For Cure 1 which entails information on treatments and medication a negative impact from connectedness on Cure 1 was identified in the Neurobrain community. This interesting counterintuitive result might be explained by the fact that too much information regarding medication and treatment is being shared and may become redundant (Lievens et al., 1999). Indeed, when examining the Neurobrain community, the level of cure 1 is the highest. Therefore, in this community highly connected patients are more frequently exposed to online postings about medication and treatment. This might lead to a cognitive overload, thereby discouraging value co-creation regarding Cure 1 (Stokes, 1983). However, concerning care-related value, the results show that patients are inclined to engage in care-related value co-creation when they are highly connected. Hence, in large networks there are more members available who are willing and able to create care-related value (Wellman, 1992). Furthermore, the technology used in the OHC facilitates the maintenance of a high number of emotional connections and fosters care-related value co-creation (Donath & Boyd, 2004). The counterintuitive negative result of integration on care might be explained by an emotional overload of the highly integrated individuals and thereby a saturation effect on care. Hence, a highly integrated patient's individual network is very dense and characterized by trustful relationships which foster the sharing of emotional content (Jayanti & Singh, 2010; Saarni, 1999). However, the confrontation with their peers' emotional stories and personal problems might trigger emotional overload which causes stress and impedes the patient's potential to co-create care-related value (Maslach & Jackson, 2013, p. 227).

4.6. Managerial Implications

Many healthcare organizations struggle with the implementation and management of digital services such as OHCs (Bain & Co., 2012; Deloitte, 2010; McKinsey & Co., 2014). Therefore, managers and policy makers need more insights into value drivers in digital services. This research responds to that need in several ways.

First, by investigating the patient's social network position as a driver for cure- and care-related value co-creation. We demonstrate that highly connected individuals contribute more in terms of cure- and care-related value co-creation with an exception for *Information on treatment and medication* which might be explained by a cognitive overload. Highly

integrated members, then, contribute less in terms of cure- and care-related value co-creation. These findings indicate interesting implications for OHC managers. Hence, to foster the creation of cure- and care-related value the OHC members' connectedness should be increased while integration should be weakened. This can be achieved by providing a large number of community threads around topics that are appealing to many members. By doing so, the discussion that emerges around each topic will contain a high number of individuals which increases the connectedness of each individual who contributes to the thread. Furthermore, the presence of a large number of threads can foster participants to contribute in multiple discussions and hence weakens their integration. Additionally, intrinsic rewarding systems such as recognition for their contributions (e.g., a badge or mention on the home page) affect members' self-esteem and consequently their activity level (Wasko & Faraj, 2005). Increased activity means contributing to several threads which increases the member's connectedness and weakens his integration.

Second, by presenting a scale to measure cognitive and affective value we provide OHC managers with an instrument to conceptualize the value created in their community. This allows them to build automatic monitoring systems which apply text mining to examine the evolution of cure and care in the community and thereby track the community's health. Hence, excessive cure with limited care or reversed might indicate a problem which needs to be adjusted by the community manager. Furthermore the scale might aid managers in empirically investigating how participant characteristics determine their potential to co-create cure- or care-related value. Hence, OHC managers might use this information to attract appropriate members.

4.7. Limitations and Further Research

The current study contains several limitations that might fuel future research. First, the current study takes a snapshot of three OHCs, thereby omitting their dynamic nature. However since OHCs are adaptive systems they should be investigated over time, taking into consideration the patient's increasing community experience (Lewis, Kaufman, Gonzalez, Wimmer, & Christakis, 2008). Future research along these lines might provide insights into how online value co-creation builds and develops over time. Investigators should examine how an individual's network position changes over time and how this affects the nature of the value co-created. Furthermore, it might be interesting to examine the effect sizes of the findings, rather than merely focusing on the direction of the results. Second, we do not make

a distinction between the type of OHC member such as ‘answer people’, ‘question people’ and ‘discussion starters’ (Hansen, Shneiderman, & Smith, 2010). However, discussion starters might guide the content of the thread and thereby influence the cure- and care-related value co-creation. By taking this into account, future research might provide insights in the relationship between member type, structural network position and value co-creation potential. Third, we rely on netnography to gather data, however the communication in online communities might comprise thousands of threads, each containing 200 or more postings. Datasets might become very large and complex, which introduces issues for capturing and storing which makes research in an online setting very time-consuming. Especially since social network analysis demands an appropriate delimitation of network boundaries which usually implies studying whole networks. Therefore, future research might apply data mining techniques to capture social network data and develop text mining models to automatically label cure- and care-related value based on our scale.

Chapter 5

Online Health Communities as Part of the Service Delivery Network: Mapping the Patient Journey

5.1. Introduction

As the digital revolution in healthcare is taking off, patients increasingly use digital services to share information and experiences about a wide range of health issues. A patient today might track his heart rate via a smartphone app, digitally schedule an appointment, or consult his electronic health record at home (Bain & Co., 2012; McKinsey & Co., 2014). Overall, about 72% of Internet users in the US seek online for health information while 16% of them try to find peers who share the same health concerns (Pew Research Center, 2013). Hence, a digital service that increasingly gains importance in the everyday life of patients is the online health community (OHC) which is used to inform about and share health-related experiences with peers and professionals.

To understand the complex role of an OHC, imagine a patient who consults an OHC before diagnosis to seek advice from peers, while for the actual diagnosis he sees his general practitioner (GP). Then, for treatment he turns to a specialist, while during self-management he mainly interacts with a nurse and returns to the OHC to provide advice. This example shows that service systems in healthcare are complex constructions consisting of various steps and actors. Within this system, the OHC is a novel actor that empowers patients to actively participate in medical decision making and thereby affects the patient's service experience with traditional service providers (Kivits, 2006). To manage and coordinate these complex systems, more insights are needed in who the different actors are that interact with the patient and how these interactions are organized in different steps (Tax, McCutcheon, & Wilkinson, 2013). Managers and policy makers need to understand the role of the OHC across several disease steps in order to facilitate its integration in the healthcare service system and create a satisfying patient service experience (S. Morgan & Yoder, 2012).

Recent service research introduces the customer journey as a framework to study complex customer experiences (Patrício, Fisk, & Constantine, 2011; Tax et al., 2013; Zomerdijk & Voss, 2010). The journey perspective recognizes that the customer experience is shaped by various service encounters (i.e., touchpoints) with a variety of service providers rather than by an isolated encounter with one provider. The patient might view these providers as resources that he can combine to obtain a satisfying experience. Hence, he has touchpoints with the traditional service provider, but also with other market facing and public sources as well as with private sources

such as peers, family and friends. All these service providers are integrated by the patient in his service delivery network (SDN), defined by Tax et al. (2013) as “two or more organizations that, in the eyes of the customer, are responsible for the provision of a connected, overall service”. From the patient’s perspective every member of the SDN contributes to his journey and helps reaching his overall objective (Tax et al., 2013). Hence, to fully understand the patient journey research needs to extend beyond the dyadic relationships (i.e., between a patient and each of his service providers in isolation) to relationships that include more than two actors (i.e., the patient and a network of interdependent service providers). Especially in a healthcare context where medical conditions are characterized by complex and interlinked causes, it is vital to identify all actors in the patient’s SDN in order to coordinate them and deliver an integrated service that raises patient satisfaction (S. Morgan & Yoder, 2012). Hence, coordination theory as proposed by Malone and Crowston (1990) offers an appropriate theoretical lens to study the SDN as a cooperative system that relies on multiple components (i.e., goals, activities, actors, and interdependencies) to coordinate members’ interactions. Thereby, the OHC, as a novel provider of information and support is an emerging part of the patient’s healthcare experience and consequently of his SDN (Nambisan, Gustafson, Pingree, & Hawkins, 2010; Nambisan & Nambisan, 2009). We define OHCs as platforms that facilitate the gathering of individuals who interact on a common health interest (Lee et al., 2003; Leimeister et al., 2006). Despite the vital role of OHCs as additional source of information and support, existing research predominantly examines the OHC as a stand-alone resource that functions independent from other service providers (Leimeister et al., 2005; Leimeister et al., 2008). Service research suggests that OHCs are part of the patients’ SDN (Tax et al., 2013) and that a patient’s need for information and support might change across his journey (Mistry, Wilson, Priestman, Damery, & Haque, 2010). Hence, to fully understand the patient journey an overview is needed of the different actors in the patient’s SDN to examine how the OHC is integrated in the service system.

The authors focus on the role of OHCs in the SDN across each step of the disease journey, and thus strive for three main contributions. First, we focus on the SDN by adopting a patient journey perspective. Thereby, we recognize that a patient interacts with a variety of providers who form a network around him (Tax et al., 2013). Especially in the case of chronic conditions, multiple providers contribute to the patient’s well-being and thereby constitute an extensive SDN. Given the complex nature of the SDN, coordination theory is used to investigate the role of the OHC in

the patient's SDN (Malone & Crowston, 1990). Applying this theory allows us to capture the complexity of the SDN in terms of the number of actors present as well as their different activities and goals. Considering the interdependencies between the different components, coordination theory aids in presenting the SDN in a clear and accurate way. Second, we adopt a patient perspective to understand how the patient journey is build up and to determine the role of the OHC in this journey. The customer journey framework is increasingly used to examine customer experiences (Patrício et al., 2011; Zomerdiijk & Voss, 2010). Thereby, we recognize that the service encounter between a patient and his provider is not an isolated event, but is embedded in series of interactions with multiple providers (Tax et al., 2013). Mapping out the patient journey offers the healthcare provider an overview of his patient's past activities and consequently provides insight in the patient's existing knowledge base. These insights might fuel more personalized service delivery since the provider might adapt information provision to the needs of his individual patient. The extent to which the patient is informed might affect adherence to the proposed medication, hence treatments might be more successful (Camacho et al., 2009; Ong et al., 1995). Third, this research contributes in a methodological way by setting up an online focus group to probe into the experience of respondents with OHCs during their patient journey. In doing so, our research instrument stays as close as possible to the setting of our research topic. The complex research subject is approached in an open way in which topics emerge next to pre-defined themes. Given the sensitive nature of high involvement services such as healthcare, a blog phase is introduced in the online focus group to build trustful relationships between the moderator and participants. Manual content analysis is complemented with automated content analysis to combine the qualities of both techniques and thereby uncover patterns in the qualitative data (Campbell, Pitt, Parent, & Berthon, 2011; A. E. Smith & Humphreys, 2006). The use of automated content analysis allows us to analyze and visualize the data as well as to reduce the subjectivity of human coding (A. E. Smith & Humphreys, 2006). Hence through this triangulation, we complement the findings from manual content analysis with automated insights which provides a more complete understanding of the role of OHCs in the patient's SDN across his journey.

To achieve these contributions, we start by reviewing literature on the service delivery network, the patient journey, online health communities and coordination theory. Next, we describe our

methodology. Finally, we discuss our findings, formulate key implications for practice, and offer suggestions for further research.

5.2. Literature Review

5.2.1. The Service Delivery Network

The service experience has long been conceptualized and examined as a dyadic interaction between the service provider and the customer (Meyer & Schwager, 2007; Surprenant & Solomon, 1987). A central assumption in this view is that the customer evaluates his experience with each single provider in isolation. However, active customers do not engage exclusively with one service provider at the time but, for example, often combine both online and offline services over time to obtain the desired health outcome. Thereby, a network of providers is formed around the patient, called the service delivery network (SDN). Hence, the active customer acts as a ‘resource integrator’ who interacts simultaneously with online and offline service providers who all contribute to the customer experience (Vargo & Lusch, 2004a, 2008). For example, consider an asthma patient whose goal is to obtain the best quality of life possible, given his condition. He might visit his regular general practitioner, but also consult a dietitian and participate in an OHC to receive social support from peers. Hence, the patient’s SDN consists of a variety of online and offline actors who shape the patient’s experience.

5.2.2. The Patient Journey

From the patient’s perspective each of the offline and online service providers in the SDN contributes to a journey for improved health (Tax et al., 2013). Thereby, the patient constructs his individual journey by combining multiple ‘touchpoints’ with his providers in a series of interactions that might extend over a considerable period of time (Patrício et al., 2011; Zomerdijk & Voss, 2010). The customer journey framework is increasingly used to examine customer experiences (Patrício et al., 2011; Zomerdijk & Voss, 2010). Yet, OHC research mainly adopts the individual service encounter as framework to study the patient’s experience (Fang et al., 2008; Keeling et al., 2015). Using the service encounter as unit of analysis might limit our understanding of the patient experience since it emphasizes a dyadic patient–provider relationship (Bitner, 1990; Laing et al., 2011). However, the patient’s experience might be shaped by several

interactions with a variety of actors such as healthcare professionals, but also family, friends and OHCs who each contribute to the objective of the patient's journey. Furthermore, by adopting the service encounter framework previous research omits that patients might demand other types of information and support across different disease steps. In contrast, the patient journey allows to map out and examine changing patient needs over a considerable period of time (Mistry et al., 2010; Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Hence, to enhance the patient's experience, service providers such as OHCs need to understand how their service fits in the patient-determined service journey (Tax et al., 2013). Consequently, service touchpoints need to be mapped out across service firms' boundaries and OHC managers need to coordinate their activities with other service providers in order to deliver better service to the customer (Patrício et al., 2011; Tax et al., 2013).

5.2.3. The Online Health Community

Next to traditional offline service providers (i.e., GP, nurse, specialist), patients add online providers such as OHCs to their SDN. In these communities patients display activities with a multitude of peers to acquire additional information and support during the diagnosis, treatment and self-management steps of their condition. Hence, the use of OHCs might be considered as a parallel service that complements the activities in traditional service encounters and thereby might be a critical member of the SDN (Laing et al., 2011).

Previous research regarding OHCs can be classified in four themes: activities in the OHC, its goals, the actors present and interdependencies that support the roll-out of activities as presented in Table 5-1 (Malone & Crowston, 1990). However, the majority of OHC studies focus on one theme and study OHCs in isolation thereby overlooking that OHCs are embedded in the patient's everyday offline life with the disease. Hence, literature regarding the goals of peer-to-peer support affirms that OHC participation has an impact on the patient's relationship with his traditional service providers. Kivits (2006), for example, states that access to online information strengthens the patient-provider relationship by establishing more trust in the expert. Furthermore, Stevenson et al. (2007) examined patients' views of the effect of the Internet on their relationship with providers and found that the Internet is perceived as an additional resource to support the existing and valued relationship with their provider. Similarly, Keeling et al. (2015) state that OHCs support the negotiation process between patients and providers since

communities are permissible spaces that redress information asymmetries. However, Fang et al. (2008) point out the danger of shifting towards consumerist patients who reduce the quality of care by placing additional demands on their provider's time and thereby imposing a negative externality on other patients. Another stream in the OHC literature looks into the integration of the online and offline world. Dannecker and Lechner (2007), for example, investigate the integration between offline and online self-help groups and conclude that the different communication channels act complementary and that their integration is perceived as important by their members. Turner et al. (2001) also investigate the complementary nature of offline and online social support and confirm that OHCs are not used in isolation, but in the context of a network of supportive relationships outside the virtual community.

There exist attempts to examine how OHCs are embedded in the entire healthcare service system. However, these studies do not recognize that a disease process is characterized by different steps that each solicit particular needs and feelings and hence, that the OHC can play different roles (Oliver, 2008). For example, Laing et al. (2011) utilize the concept of the service encounter to explore the interplay between online communities and the formal, face-to-face service encounter. By utilizing the service encounter as framework, the authors apply a rigid interpretation of the disease process since service encounters are embedded in a series of exchanges that may extend over a considerable period of time (Patrício et al., 2011; Zomerdijk & Voss, 2010). Hence the concept of the patient journey appears to be more suited to investigate how OHCs are embedded in the healthcare service system.

Table 5-1 Overview of OHC research

Authors	Activities			Goals			Actors		Interdependencies
	Diagnosis	Treatment	Self-Management	Emotion	Cognition	Behavior	Patients	Providers*	
Barak et al. (2008)				X	X	X	X		X
Beaudoin et al. (2007)	X	X		X	X				
Cline et al. (2001)							X		X
Demiris (2006)					X		X	X	X
Eysenbach et al. (2005)				X	X		X		
Keeling (2015)						X	X	X	
Kivits (2006)	X	X			X		X	X	
Laing et al. (2011)					X	X	X	X	
Leimeister et al. (2005)							X		X
Leimeister et al. (2008)				X	X		X		
Loane et al. (2013b)							X		X
Loane et al. (2014)				X	X		X		
Maloney-Krishmar et al. (2005)				X	X		X		X
Mo et al. (2009)							X		
Preece et al. (2001)				X			X		
Stevenson (2007)					X		X	X	
Turner et al. (2001)				X	X		X	X	
Welbourne et al. (2013)	X	X		X	X		X		
Winkelman et al. (2003)			X		X		X	X	

Note: * refers to offline providers surrounding the OHC.

5.2.4. Coordination theory

Coordination theory, a principle often used to describe collaboration mechanisms (Euerby & Burns, 2014), provides a suitable framework to assess the role of OHCs in the SDN across different steps of the patient journey. Since patients perceive the OHC as part of the SDN (Johnson & Ambrose, 2006), its activities need to be coordinated with other members of the SDN to create a satisfying service experience. Malone and Crowston (1990) identify four components that aid in coordination, which they define as “the act of working together harmoniously”. We utilize the components to assess the role of the OHC from the patient’s perspective. The first component, *goals*, relates to the patient’s emotional, cognitive and behavioral needs that should be satisfied by the OHC. Hence, emotion interacts with cognition and motivates behavior (Dolan, 2002). The second component, *actors*, relates to the SDN members that complement the service of the OHC and contribute to the overall objective of the patient’s journey. Since the cause of many diseases is a complex puzzle of physical, psychological and environmental dimensions, patients reach out to multiple traditional (e.g., doctor) and alternative service providers (i.e., OHC) who address all their needs in an integrated way (Johnson & Ambrose, 2006). The third component, *activities*, describes the steps in the patient journey from pre-diagnosis to diagnosis, treatment and self-management (Oliver, 2008). The fourth component, *interdependencies* entails enablers for the activities. Hence, interdependencies facilitate the activities and the transition between activities (Raposo, Magalhães, Ricarte, & Fuks, 2001). The authors utilize coordination theory to construct a framework that aids in examining the role of OHCs in the SDN across the patient journey (see Table 5-2).

Table 5-2 Coordination theory framework

Activities during the patient journey	Pre-diagnosis and Diagnosis	Treatment	Self-management
Goals of the patient			
Complementary actors			
Interdependencies that enable the activities			

5.3. Methodology

5.3.1. Overview

To unravel the role of OHCs in the SDN across each step of the disease journey, we have set up an online focus group and invited 124 asthma patients to share their experiences regarding their service journey and the interplay with OHCs. Before the focus group started, participants were invited to attend a kick-off session where the purpose and operation of the group were explained. The online focus group then ran for 3 weeks and included one week of blogging complemented by two weeks of online discussions. The first week of blogging was deliberately included to develop a trustful relationship between the community moderator and each of the participants. During this period, more general questions regarding asthma coping and online community use were presented. Afterwards, 2 weeks of discussion were rolled out to retrieve insights in the role of online communities during the patient’s asthma journey. Thereby, the discussions were centered around three disease steps: (1) (pre-)diagnosis, (2) treatment, and (3) self-management (for an example of a discussion, see Appendix F). During each of the disease steps, participants were probed with questions regarding the patient journey, their emotions and finally the role of the OHC. An overview of community activities is provided in Table 5-3. A more elaborate overview, including the precise questions, can be found in Appendix G.

Table 5-3 Community activities

Week	Activity	Step	Topic
Week 1	Blog		Asthma coping
Week 2	Discussion	Diagnosis	<ul style="list-style-type: none"> • Patient journey • Emotions • Role of OHCs
		Treatment	<ul style="list-style-type: none"> • Patient journey • Emotions
Week 3	Discussion	Treatment (Continued)	<ul style="list-style-type: none"> • Role of OHCs
		Self-management	<ul style="list-style-type: none"> • Patient journey • Emotions • Role of OHCs

5.3.2. Sample

Via a recruitment survey 124 participants from the UK were selected to participate in the asthma community, based on two main criteria: (1) they were diagnosed with asthma, a chronic disease that requests a complex service system, and (2) they had experience with participation in an existing OHC. Asthma was chosen as focal condition since it is a chronic and long-term lung disease (National Heart Lung and Blood Institute, 2014) which suggests that the participants have developed profound knowledge about their treatment and coping mechanisms. Furthermore, the researcher who functioned as community moderator suffered from childhood asthma which facilitated the communication with the participants. From the initial pool of 124 recruits, 60 participants logged in on the asthma community and contributed actively to the discussions. The participants suffered on average 19 years from asthma (s.d. 11.5), 61.7% visited their existing online community 2-3 times a month or more and 56.6% posted there more than 2-3 times a month. Furthermore, the majority suffered from intermittent to persistent-mild asthma as measured by the ‘National Heart, Lung and Blood Institute’ Guidelines for the Diagnosis and Management of Asthma (US Department of Health and Human Services, 2007, p. 72). Table 5-4 describes the data gathered in the community. Table 5-5 provides an overview of the variables that describe the sample.

Table 5-4 Data description

Number of active participants	60
Number of activities (i.e., discussion threads)	35
Total number of postings	1150
Average number of postings per participants	19 (s.d.=9)
Average length of postings (in words)	60 (s.d.=45)

Table 5-5 Sample description

Demographic information	<i>Gender</i>	M: 40% F: 60%
	<i>Age</i>	18-24: 16.7%
		25-34: 38.3%
		35-44: 25.0%
		45-54: 6.7%
55-69: 13.3%		
Asthma information	<i>Severity</i>	Intermittent: 25.0%
		Persistent-Mild: 45.0%
		Persistent-Moderate: 21.7%
		Persistent-Severe: 8.3%
	<i>Diagnosis age</i>	Childhood asthma: 57%
		Adult asthma: 43%
	<i>Time since diagnosis</i>	M: 19.4 years s.d.: 11.5 years
OHC information	<i>Frequency of visiting</i>	Less than once a month: 20.0%
		Once a month: 18.3%
		2-3 times a month: 21.7%
		Once a week: 10.0%
		2-3 times a week: 15.0%
	<i>Frequency of posting</i>	Daily: 15.0%
		Less than once a month: 31.7%
		Once a month: 11.7%
		2-3 times a month: 16.7%
		Once a week: 18.3%
		2-3 times a week: 13.3%
		Daily: 8.3%

5.3.3. Data Analysis

After 3 weeks of intense blogging and discussing, the community contained 1150 postings by 60 participants. To analyze this vast amount of data, the authors used a systematic approach as formulated by Corbin & Strauss (2008). In a first step, open coding is applied which means that the authors did not establish a coding scheme upfront, but rather let the codes emerge during the coding process. Given the limited literature present on the role of OHCs in SDN, open coding is selected to reach a theoretically relevant understanding of the phenomena of interest. Online postings were defined as unit of analysis and labelled with relevant codes that reflected the research questions, thereby staying as close to the data as possible (Spiggle, 1994). In a second step, axial coding is applied which means that the concepts identified through open coding are related to each other through comparative analysis. Thereby, incidents will be compared with each other for similarities and differences. However, open coding and axial coding take place simultaneously as the analysis proceeds (Corbin & Strauss, 2008). The coding was done by employing a tagging tool build in the research community software of IdeaStream (Dub, 2015). Next to the traditional approach of Corbin & Strauss (2008) the automated content analysis tool, Leximancer, was used to visually depict and interpret the data. Via machine-learning techniques Leximancer performs conceptual and relational analysis which allows us to discover the main concepts in a text, and how they relate to each other (Rooney, 2005). Next, Leximancer builds a thesaurus of words that are closely related to each of the concepts that were identified. The text is then visually displayed in a concept map which displays the main concepts and their interrelationships. Thereby, concepts are more than key words, but rather a collection of words that ‘travel together’ (Campbell et al., 2011). Finally the concepts extracted from the text are displayed on a map that shows the relative importance of concepts, and the strengths between them.

5.4. Results

During pre-diagnosis activities, patients experience symptoms and discomfort which might raise suspicion about a serious disease, but no formal diagnosis is established yet (Widerman, 2004). During diagnosis and treatment activities, then, a diagnosis is formulated by a healthcare provider and a treatment suggested. Since the patients in our sample mainly suffer from intermittent to

moderate asthma, similar to the majority of global asthma sufferers (Asthma UK, 2015b), diagnosis and treatment is mainly performed by the patient's GP rather than via a pulmonologist in hospital.

The patient journey can be interpreted in a horizontal or a vertical way. In this study, we mainly adopted a vertical mindset, meaning that we discussed the components of coordination theory in each step of the journey rather than focusing on the transitions and changes between the steps, i.e. a horizontal way of thinking. The vertical mindset is induced by the use of coordination theory where we operationalized 'activities' as the different steps in the patient journey. Similarly, the discussions in the online focus group were concentrated on each step which fosters a vertical mindset. Nevertheless, by visually representing the results in figure 5-6, changes between steps in the journey might be deduced.

5.4.1. Diagnosis

5.4.1.1. Pre-diagnosis: before diagnosis

Goals

Emotional Needs. Before the formal diagnosis of asthma, patients experience many symptoms which prevent them from continuing with their day-to-day activities. Not knowing what they are experiencing and what is going on makes them frustrated and scared. As one participant puts it: *"I was very frustrated before my diagnosis as I didn't realize what I was dealing with. I was scared especially with the shortage of breath, I thought I was going to die."* (madmax, persistent-moderate asthma). Hence, patients are in need for social support and find this in OHCs (Yoo et al., 2014). By explaining and describing their symptoms, patients realize they are not alone with their problem: *"I think that being part of the online community helps so much. Knowing someone else who has been having problems or just understands how you are feeling is great. Not so lonely."* (Cromford 6, persistent-mild asthma).

Cognitive Needs and Behavioral Needs. Participants perform a general information search about their symptoms before the first appointment with their GP, thereby aiming to understand their problem. This initial information search fuels the interaction during the patient–doctor encounter afterwards. Hence, patients prefer to display an active attitude and be informed in order to

construct a dialogue with their doctor rather than one-way information sharing (Keeling et al., 2015). As noted by one patient: *“I’d certainly recommend reading about the illness so that you’ll be engaged in a two-way process rather than simply hearing a lecture on asthma!”* (MartynJ, *intermittent asthma*). Informed patients are prepared to ask their doctor questions which benefits the diagnosis process and helps the patient in making informed decisions. In general, several patients point out that OHCs made them aware of the importance of monitoring symptoms and triggers in order to help the doctor in establishing a thorough diagnosis. As one patient mentions: *“I would say to keep a diary of what you feel triggers you so you can give the doctor a thorough report.”* (CarrieBeth, *persistent-mild asthma*). Thereby, comparing symptoms in the OHC allows patients to self-diagnose: *“I had an asthma attack and did not know what it was. Searching the forums helped me to self-diagnose and I was able to inform the doctor what had happened.”* (daffystjob, *persistent-moderate asthma*).

Actors in the SDN

Prior to diagnosis the patient’s SDN consists of the GP and family & friends. During pre-diagnosis the GP might be considered as a latent actor in the SDN. Hence, the patient knows the GP and even refers to him as ‘my’ GP as illustrated by following quote: *“I would search for information so I could tell my GP what I think or know.”* (emmalouise, *persistent-mild asthma*), but does not actively consult him regarding his asthma symptoms. Friends & family, then, are actively present before diagnosis and support the patient in coping with his symptoms. However, no relationship exists yet between the doctor and the patient’s family and friends.

Interdependencies

Before the formal diagnosis a patient experiences unfamiliar symptoms, however he needs to recognize the problem and its severity in order to consult a GP. As posited by one participant family & friends might play a crucial role in identifying and recognizing the problem: *“Family and friends were very supportive both before and after diagnosis. Some recognized the symptoms before and therefore helped me with recommendations about easing and stopping attacks.”* (mickyxxx, *intermittent asthma*). This is in line with research investigating the factors that influence the decision to seek healthcare (Andersen, Paarup, Vedsted, Bro, & Soendergaard, 2010; Khraim & Carey, 2009).

Touchpoints with the SDN during pre-diagnosis

During pre-diagnosis the main touchpoint in the patient’s journey are family and friends. The touchpoint and role of the OHC are presented in table 5-6.

Table 5-6 Touchpoint during pre-diagnosis and role of OHC

Touchpoint	Role of OHC
Talk about symptoms with friends and family.	Patients check symptoms online, in the OHC, to ensure that there is something wrong.

5.4.1.2. During diagnosis

Goals

Emotional Needs. After being diagnosed, patients are relieved. However, when they comprehend the chronic nature of the condition and realize that it cannot be treated, but rather controlled, patients tend to be upset and sad. As one patient explains: *“When they diagnosed asthma I was a little upset about it as I thought I would have it for life.”* (cherylanne, persistent-mild asthma). The social support in the OHC aids patients in accepting the condition: *“I only started looking through online forums when I was first diagnosed with Asthma because I couldn’t really believe I actually had it! [...] However, it [OHC participation] did help me to understand the symptoms and realize myself that, yes, I did have asthma.”* (cherylanne, persistent-mild asthma).

Cognitive Needs and Behavioral Needs. Once diagnosed, patients take a critical stand towards the information provided by their doctor and often go online to complement or validate his expertise which is in line with the concept of the informed patient (McMullan, 2006). Complementary information predominantly deals with the day-to-day disease experience or experiences that only peers can share: *“Look for information after seeing a doctor as you may find useful information that the doctor did not tell you, for example effects of the medication.”* (Gothlass, persistent-mild asthma). Likewise, validation of the doctor’s explanation is advised: *“You should do research to cross-check what the doctor or professional told you.”* (Neptune, persistent-moderate asthma). Hence, these findings demonstrate that patients combine online and offline sources to satisfy their need for information, yet remain critical. Thereby the doctor is no longer perceived as an omniscient authority who should be obeyed, but as a human-being with

his own shortcomings: *“I think it's important to do the basics of self-diagnosis before seeing professionals. [...] Also doctors don't always know much about conditions, or might have bigoted opinions, so this way they can't push you around as much.”* (Neptune, persistent-moderate asthma). Similarly, online information is used with precautions and critically assessed in collaboration with the GP: *“I would also advise that information gathered online should be checked with their GP as not all sources may be reliable.”* (Marymcd, persistent-mild). Hence, online information does not undermine the doctor's authority as feared by healthcare professionals (Nwosu & Cox, 2000; Risk & Petersen, 2002), but rather acts as a complement. Hereby, medical knowledge is integrated with experiential information gathered in the OHC.

Actors in the SDN

In general, patients are diagnosed by their GP in collaboration with an asthma nurse who performs several lung function and breathing tests (Montnemery et al., 2002). Next to their professional service providers, family & friends are important members of the SDN. Since asthma might be hereditary (Leigh & Marley, 2013), patients mention family members with asthma as a vital source of support: *“My daughter was especially helpful and supportive as she, herself had previously been diagnosed with Asthma so she had knowledge of things such as treatments, possible triggers and adjustments that I may have to make.”* (Marymcd, persistent-mild asthma). Likewise friends are an important source of support: *“Friends often understand my condition and be with me in a supportive way.”* (prisam, persistent-mild asthma). From a network perspective, strong reciprocal relationships exist between the GP and the nurse and between the GP and the patient's family. The doctor and nurse have direct, in-depth and frequent interactions given their collaboration on the patient's diagnosis. While the GP initiates a preliminary diagnosis, the nurse performs the necessary testing and together they establish a correct diagnosis. Given the hereditary nature of asthma, family is often present during doctor consults and thereby develops a strong relationship with the provider.

Interdependencies

The GP and asthma nurse establish a diagnosis in collaboration. The doctor merely provides expert knowledge while the asthma nurse carries out the necessary testing and is a source of comfort for the patient, thereby putting him at ease which aids in coping with the diagnosis: *“I*

have every faith in my asthma nurse. I know she has all my information to hand and has my best interests at heart.” (madmax, persistent-moderate asthma). During diagnosis, family & friends provide the necessary support to the patient which aids in calming down: “My family is always on hand for emotional support as well as any other support I should need. Sometimes all it can take is a little chat and I can feel so much better than keeping anything that could be worrying myself about locked up inside, and after my stress levels drop instantly and I can relax.” (simoneeze, persistent-mild asthma).

Touchpoints with the SDN during diagnosis

During diagnosis, the main touchpoint in the patient’s journey are consultations with the doctor, asthma nurse and family & friends. The touchpoint and role of the OHC are presented in table 5-7.

Table 5-7 Touchpoints during diagnosis and role of OHC

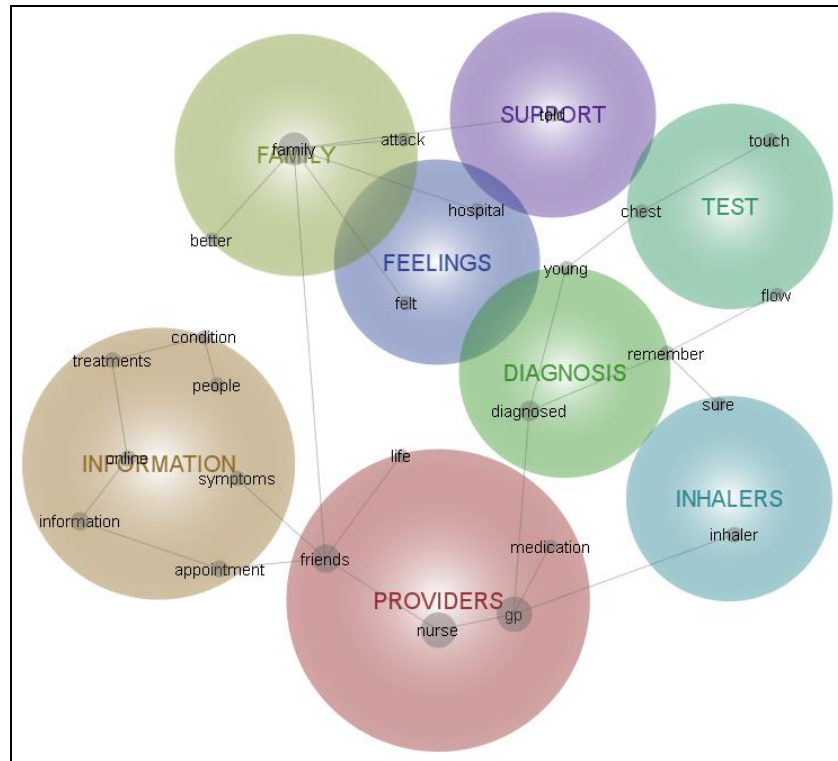
Touchpoint	Role of OHC
Doctor appointment.	Information gained in the OHC fuels questioning the doctor.
Tests by asthma nurse.	The information gained in the OHC prepares the patient so that he knows what kind of testing he might expect.
Consult family and friends.	Peers in the OHC provide patients with additional social support.

Automated content analysis of the pre-diagnosis and diagnosis step

Since the pre-diagnosis and diagnosis steps of the patient journey were queried in one discussion room in the research community, these two steps are intertwined in one body of text. Hence, pre-diagnosis and diagnosis are simultaneously analyzed by means of Leximancer. Hereby, the automated content analysis confirms several of our qualitative insights. *Information* is an important theme as indicated by the size of the circle, and its composition affirms that patients focus on information gathering regarding *symptoms* and *treatment*. Moreover, the close collaboration between the asthma nurse and GP is depicted as well as the finding that patients view the *nurse* as a friend, while the *GP* is perceived as focusing on diagnosing and medication. Finally the role of friends as problem identifiers is signified by a link between *friends* and

appointment, suggesting their vital role in recognizing the problem and advising the patient to make an appointment with their service provider.

Figure 5-1 Visual representation of content analysis: pre-diagnosis and diagnosis



5.4.2. Treatment

Goals

Emotional Needs. The treatment activities elicit different emotions by patients. They are relieved and hopeful, since the received medication improves their quality of life and allows them to continue with their daily activities: *“I did feel relieved as the treatments what had been prescribed made me feel a lot better like felt normal again.”* (gina888, persistent-mild asthma). Moreover, with the correct treatment, patients feel in control of their condition: *“Now I am aware of what I need to do to keep my asthma under control I find it to be a bit of a hindrance.”* (Jennycat, persistent-moderate asthma). Then again, patients feel fear realizing that they have to take their medication for the rest of their lives: *“I then felt fear as I realized that this was a lifelong issue and not one to be looked at lightly as it can be very serious if I'm not careful.”*

(mickyxxx, *intermittent asthma*). The OHC is consulted when patients are going through a difficult period such as an asthma attack or when the condition aggravates: *“I had read around the subject before diagnosis, but afterwards after having a little episode of feeling run down and generally the condition being bad, I went onto Asthma UK which had loads of forums and I felt instantly at home.”* (becky17, *persistent-moderate asthma*). Thereby, the social support from peers creates awareness that they are not alone in dealing with this disease: *“I have been more aware that it is a common illness and I am not alone.”* (Danson16, *persistent-mild asthma*).

Cognitive Needs. During treatment activities patients feel a need for additional information about the medication they are prescribed and continue to monitor and investigate their triggers and symptoms. Moreover patients use the OHC to examine the disease progression and reported side-effects from peers with a similar treatment plan: *“When I have been put on different medication I always look online for how it's worked for other people.”* (nikki87, *persistent-moderate asthma*). Hence, comparing and making sense of differences is an important part of the patient's online interactions: *“Good to look online and see if others have similar problems with the medication offered.”* (becky17, *persistent-moderate asthma*). This finding is in line with previous research stating that medication use and comparing results is a major theme in OHCs (Dahl, 2006). Furthermore, patients display an active attitude and explore alternative treatments via the OHC (Macias, Lewis, & Smith, 2005) which might be used as input for the patient–doctor encounter: *“Also found information which talked about steroid treatment and other non-conventional methods like acupuncture and meditation.”* (batswarrior3, *intermittent asthma*). Similar to the diagnosis activities, patients value the experiential information in the OHC which complements their doctor's expert knowledge: *“I think facts are relatively easy to find, but what is really interesting is how others coping in ‘real life’ are handling and coping with the condition, so yes testimonies from people definitely are part of it.”* (becky17, *persistent-moderate asthma*). Thereby personal tips on how to cope with certain aspects of the disease are invaluable: *“Someone told me to stick with my treatment and to try sitting up on a load of pillows to help with my breathing.”* (toxcity02, *intermittent asthma*).

Behavioral Needs. Participation in OHCs improves the communication between patient and doctor in many ways (Keeling et al., 2015; Kivits, 2006). The experiential information that patients retrieve online fosters them to ask their doctor for further explanation and advice.

Thereby, online information allows the patient to make his questions very specific and accurate: *“By looking at the websites, I made the decision to go to my doctor, as I never actually realized how mould can affect asthma and rhinitis.”* (Danson16, persistent-mild asthma). Additionally, the information retrieved from OHCs allows patients to make suggestions to their doctor: *“It changed some of my interactions with healthcare providers as I was able to suggest some things that might help with treatment myself.”* (helen000, persistent-mild asthma). Hence, the information from OHCs increases the patient’s understanding of his doctor’s explanations: *“It helped me understand some of the things the doctor mentioned such as different types of inhalers and triggers.”* (cheryllanne, persistent-mild asthma). Besides improved communication, OHC participation might impact the treatment decisions and treatment adherence of patients (Keeling et al., 2015). Interacting with peers online makes some participants aware of how serious the disease is: *“I was made aware of the seriousness of asthma as before I didn't think it was any more than an inconvenience to me!”* (cheryllanne, persistent-mild asthma). Consequently, this enhanced awareness fosters patients to be more precise regarding their medication intake: *“Through talking to others found out more about triggers [...]. This made me more aware of necessity to carry inhaler with me as used to wait till home to take rather than at the time.”* (Soundoftherain, persistent mild asthma). In the end, online communication increases the confidence in the treatment which might favorably influences health outcomes: *“The information I got and examples from other people using the same inhalers as me made me confident that they would work.”* (Scorpiodragon76, persistent-moderate asthma).

Actors in the SDN

The treatment is prescribed by the GP, while the asthma nurse takes time to explain how the medication functions (Morice & Wrench, 2001). As described by a patient: *“My Doctor wasn't a great source of comfort, as he basically gave me an inhaler and showed me how to use it, so I was frustrated with that. The asthma nurse put my mind at rest by explaining the inhalers.”* (anpa25, intermittent asthma). Patients are usually prescribed a combination of relieve and preventer inhalers complemented by steroids and breathing exercises (Asthma UK, 2015a). For the majority of participants the treatment process is one of trial-and-error as indicated by following explanation: *“I was prescribed an inhaler as well as shown how it worked/how to use it - it was a bit of trial and error with different inhalers - a little tedious but necessary.”* (firetree,

persistent-mild asthma). Hence, coordinating the actions of the SDN members—here, the GP and asthma nurse—is vital in discovering the most effective treatment. During the treatment activities another service provider is added to the SDN, the pharmacist, who fulfils an important role as information source: “*Pharmacist would help with basic asthma advice and care of my inhalers and general questions.*” (*lolotoo, persistent-mild asthma*). Family & friends are the main providers of support during treatment activities. For childhood asthma, the parents play an important role in treatment adherence: “*I did get lots of help from my parents, always making sure I took it on time and also used the inhalers correctly.*” (*G-owen, persistent-severe asthma*). From a network perspective, the strong relationships between the GP, nurse and family remain while the pharmacist is added to the SDN. However, the relationship between the GP and pharmacist is rather weak and indirect via prescription notes.

Interdependencies

As indicated before, the GP focuses on prescribing and briefly explaining the treatment plan, however, patients demand more in-depth information and practical tips to become familiar with the treatment. Moreover when changes are made to the treatment, patients want to understand the reason and demand additional information: “*Changed from Ventolin to salbutamol without explanation, but me being me asked the GP at the time! [...] It would be nice if these things were explained to us!*” (*Cat10, persistent-severe asthma*). Hence, similar to the diagnosis step, the asthma nurse is a provider of informational and emotional support: “*I'd recommend getting in contact with your asthma nurses and talk to them. They are trained professionals who can answer factual questions, but also provide emotional support.*” (*KatjaStout, intermittent asthma*). Family & friends continue to play an important role as providers of emotional support. Moreover, given the hereditary nature of asthma (Leigh & Marley, 2013), family members might join doctor appointments in order to collaborate with the doctor as a team: “*I knew I should see the nurse more regular for both my son's treatment and my own. So this meant we could go in for a double appointment and work as a team.*” (*lolotoo, persistent-mild asthma*). The pharmacist who joins the SDN during treatment activities reassures patients by answering their questions and providing additional information regarding medication: “*I also found that my local pharmacist was also a big help with tips for treatments etc.*” (*Marymcd, persistent-mild asthma*).

Touchpoints with the SDN during treatment

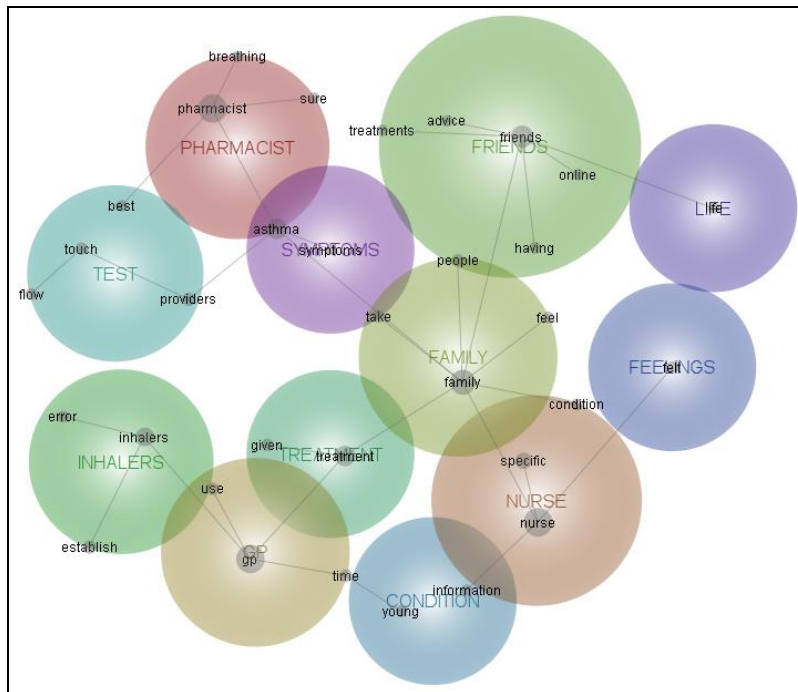
During treatment, the main touchpoint in the patient's journey are consultations with the doctor, follow-ups with the asthma nurse, pharmacy visits and consultations with family & friends. The touchpoint and role of the OHC are presented in table 5-8.

Table 5-8 Touchpoints during treatment and role of OHC

Touchpoint	Role of OHC
Doctor appointment to discuss treatment.	Participation in the OHC fosters informed decision making and increases adherence to treatment.
Follow-up by asthma nurse: explanation of treatment.	Peers in the OHC provide additional information.
Visit the pharmacist to buy medication.	Participation in the OHC fosters questioning the pharmacist regarding treatment and medication.
Consult family and friends for moral support.	Peers in the OHC provide patients with additional social support.

Automated content analysis of the treatment step

The Leximancer analysis confirms an important supportive role from the patient's *friends* which is depicted by the size of the respective circle. Furthermore, the *pharmacist* is added to the SDN and his role as assuring actor is illustrated. The *GP* is yet again associated with treatment, however here we see that this concept is also connected to 'time' illustrating the time constraints of the GP. Furthermore, the role of the *nurse* as information provider and source of emotional support is confirmed.

Figure 5-2 Visual representation of content analysis: treatment

5.4.3. Self-management

Goals

Emotional Needs. Once the condition is under control and the patient enters self-management activities, he accepts his disease and consequently the fact that he has to manage it on a daily basis: *“I don’t get too worked up about it as it is just a fact of life - I’m going to be stuck with it until either it just goes or a medical breakthrough is found.”* (mrbloppy, persistent-mild asthma). However, on bad days, negative emotions come to the front: *“On good days I feel quite proud I’m managing, other days I feel upset and downtrodden.”* (Danson16, persistent-mild asthma). Hence the daily management of asthma might be frustrating: *“It can be a bit frustrating having to take medication on a daily basis and having to remember which and when to take each. It can also be quite annoying having to keep record of your symptoms and things like peak flow test etc.”* (Marymcd, persistent-mild). It seems that participants with childhood asthma experience less difficulty in the acceptance process of this chronic condition and the accompanying management part: *“I’ve got older. I’ve had asthma for as long as I can remember so the management side is kind of normal to me.”* (toxcity02, intermittent asthma). Nevertheless, the OHC provides a place where all patients can vent their feelings: *“I often log on to vent as well, if I’m going through a*

bad patch and want to chat with people with the same issues it's sometimes a bit easier to talk to people you don't know, not all of my family can relate to how I'm feeling all of the time.” (helen000, persistent-mild asthma).

Cognitive Needs. During self-management activities, patients experience a need for information when they encounter new symptoms or when their condition gets worse: *“I wanted to find other ways of self-management after a really bad asthma attack.”* (Scorpiodragon76, persistent-moderate asthma). Thereby, patients mainly focus on information regarding medication: *“Developing another condition and wondering if my asthma medications would interact with medications needed for the other condition.”* (Jennycat, persistent-moderate asthma). Also during self-management experiential information is highly valued by patients: *“I think facts are relatively easy to find, but what is really interesting is how others coping in "real life" are handling and coping with the condition.”* (beckyl7, persistent-moderate asthma).

Behavioral Needs. Experiences from peers make people more aware of what might be a trigger and avoid it, which is pivotal in asthma management (Vernon, Wiklund, Bell, Dale, & Chapman, 2012): *“Reading what was said about asthma and the connection with pollution, made me more aware of where I was living and how this could be affecting me. It also contributed to me moving further out of town.”* (anpa25, intermittent asthma). Likewise, it stimulates them to regularly make appointments for a check-up: *“Made me more aware of the need to have regular checks with the asthma nurse.”* (grandmax3, persistent-mild asthma). Thereby, patients learn how important it is to track their symptoms: *“It gave me new ways of self-managing my asthma such as keep a diary of my symptoms and when they happened and how they affected me.”* (Scorpiodragon76, persistent-moderate asthma). In doing so, feedback loops might be installed from the self-management stage to the treatment stage. Hence, when patients indicate during the self-management stage that their symptoms worsen, the asthma nurse might refer them back to the GP for treatment adjustment. After patients adjusted to their altered treatment, they return to the self-management stage. Furthermore, online interaction with peers points patients towards the potential of alternative treatments: *“I received a recommendation for yoga with breathing exercises from another community member which has helped me immensely.”* (daffystjob, persistent-moderate asthma).

Actors in the SDN

When the condition is under control, patients enter the self-management activities where they have to avoid and report triggers, keep a close eye on their symptoms, and take their medication (Kirby et al., 2014). Thereby, the patients only interact with their GP when there are changes in their condition or when they need new prescriptions. The asthma nurse is the most important source of information and support during self-management, as illustrated in following statement: *“I go to see my asthma nurse every 3 months. I look upon her as a friend who spends time with me, doesn’t rush me and generally understands and has sympathy for me. The GP, although more qualified, doesn’t have the time to spend and listen.”* (madmax, persistent-moderate asthma). In general, family members and friends are an important source of support, and especially in the case of childhood asthma, parents play a pivotal role: *“I would say my parents—who I was living with at the time while I was going through the self-management stage—they made sure I used my inhaler regularly and also took it with me when going out.”* (gina888, persistent-mild asthma). Also school teachers and later on employers adapt to the patient’s situation and aid in managing the disease: *“The support I have received over the years has been fantastic, from teachers at school to work colleagues and family members. I have never felt alone when I’ve felt unwell.”* (mejulie, persistent-moderate asthma). Furthermore, participation in the OHC fosters patients to try other treatments and thereby, additional service providers such as dietitians, yoga instructors and personal trainers are added to the SDN: *“I received a recommendation for yoga with breathing exercises from another community member which has helped me immensely. Since I have started participating in the community, I stick to my daily yoga routine because each day I am reminded that I need to do it to reap the benefits.”* (daffystjob, persistent-moderate asthma). From a network perspective, we identified strong relationships between the patient and each of the other members in the SDN, being the asthma nurse, family & friends and additional service providers. However, no formal relationship exists between the additional and traditional healthcare providers. This gap might be caused by the patient who consults additional providers on his own initiative without consulting the GP or asthma nurse.

Interdependencies

During self-management, the asthma nurse is the first person to contact when issues arise regarding treatment and disease management (Pinnock et al., 2015). She uses an empathic

approach to provide information and support, hence patients perceive her as a friend who has time for them: *“I like seeing the nurse. She is now a friend and knows the family well. [...] I prefer to chat to her and she seems to have more time to go through things.”* (lolotoo, persistent-mild asthma). Family & friends are present to remind patients in taking their medication and discuss their worries. The additional providers included in the SDN such as dietitians, personal trainers and yoga instructors provide the patient with a feeling of control and the assurance that they do everything possible to manage their disease: *“After over thirty years with asthma I can now say that my asthma is under control [...]. I spoke to other providers such as homeopathic doctors. I take regular exercise with a trainer to build my lung capacity and I control my diet [...].”* (smd, intermittent asthma).

Touchpoints with the SDN during self-management

During self-management, the main touchpoint in the patient’s journey are follow-up meetings with the asthma nurse, consultations with family & friends and additional providers. The touchpoint and role of the OHC are presented in table 5-9.

Table 5-9 Touchpoints during self-management and role of OHC

Touchpoint	Role of OHC
Follow-up meeting with asthma nurse.	Peers in the OHC stress the vital role of the follow-up appointments with the asthma nurse.
Receive support from family and friends.	Peers in the OHC provide patients with additional social support.
Consult additional providers.	Patients receive information about additional therapies via their peers in the OHC.

Automated content analysis of the self-management step

During self-management the *nurse* continues with the provision of emotional support while several providers have been added to the SDN. By providing extra information and aiding in managing the condition, these providers allow the patient to take control over his condition.

Figure 5-3 Visual representation of content analysis: self-management

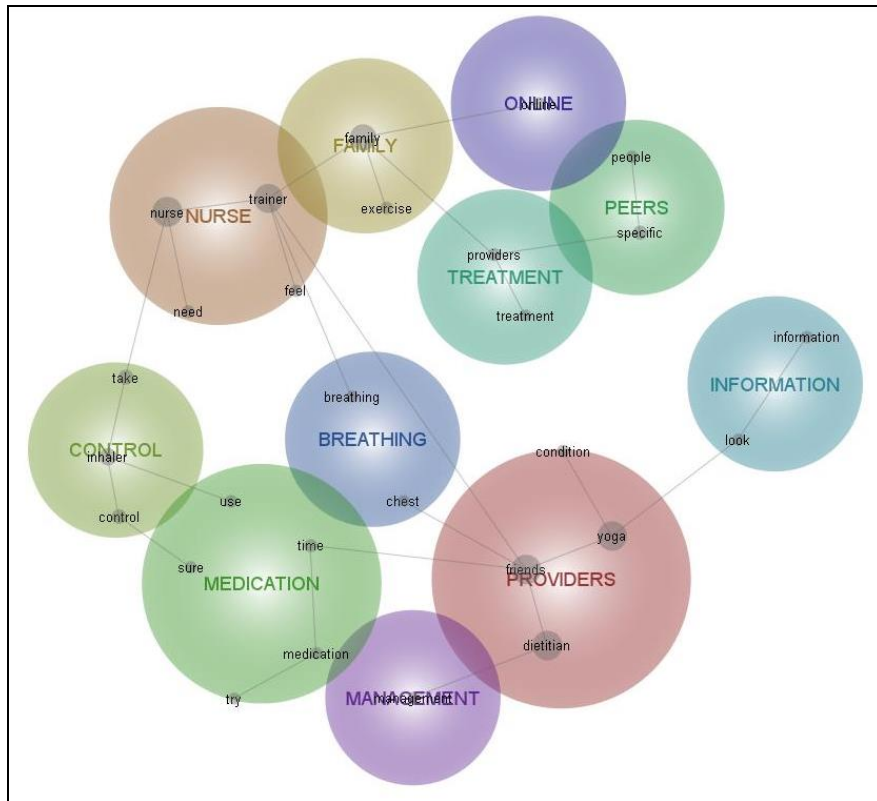


Table 5-6 provides an overview of the components of coordination theory as applied to OHCs across the patient journey.

Table 5-10 Application of coordination theory on OHCs across the patient journey

Activities	Pre-diagnosis	Diagnosis	Treatment	Self-management
Goals	<p>Satisfying emotional needs</p> <ul style="list-style-type: none"> • Emotional support ➔ Frustration, scared, lonely <p>Satisfying cognitive needs</p> <ul style="list-style-type: none"> • General information • Info on symptoms <p>Satisfying behavioral needs</p> <ul style="list-style-type: none"> • Keeping a trigger diary • Self-diagnose 	<p>Satisfying emotional needs</p> <ul style="list-style-type: none"> • Emotional support ➔ Relieved, sad <p>Satisfying cognitive needs</p> <ul style="list-style-type: none"> • Info on potential treatments • Complement and validate expert's explanation <p>Satisfying behavioral needs</p> <ul style="list-style-type: none"> • Information fuels questioning the HC provider 	<p>Satisfying emotional needs</p> <ul style="list-style-type: none"> • Emotional support ➔ In control, fear <p>Satisfying cognitive needs</p> <ul style="list-style-type: none"> • Specific information • Info on side-effects • Info on triggers and symptoms • Info on alternative treatments • Comparing <p>Satisfying behavioral needs</p> <ul style="list-style-type: none"> • Good communication with doctor • Participate in treatment decisions • Adhere to treatment 	<p>Satisfying emotional needs</p> <ul style="list-style-type: none"> • Emotional support ➔ Acceptance, frustration • Venting <p>Satisfying cognitive needs</p> <ul style="list-style-type: none"> • Info on symptoms and triggers • Info on additional treatment <p>Satisfying behavioral needs</p> <ul style="list-style-type: none"> • Increased awareness about triggers • Regular check-ups with nurse • Tracking symptoms • Adding alternative therapy
Actors	<ul style="list-style-type: none"> • GP • Family & friends 	<ul style="list-style-type: none"> • GP • Nurse • Family & friends 	<ul style="list-style-type: none"> • GP • Nurse • Family & friends • Pharmacist 	<ul style="list-style-type: none"> • Nurse • Family & friends • Yoga • Trainer • Dietitian • Homeopathic doctor
Interdependencies	<ul style="list-style-type: none"> • Problem identification by friends & family 	<ul style="list-style-type: none"> • Expert knowledge by the GP • Comfort by the nurse • Support by family & friends 	<ul style="list-style-type: none"> • Treatment plan by the GP • Info and support by the nurse • Support by family & friends • Reassurance by the pharmacist 	<ul style="list-style-type: none"> • Empathy by the nurse • Support by family & friends • Control by the additional service providers

Note: The journey is depicted from the perspective of the OHC. The actors depicted in this table are the offline actors that surround the OHC in the SDN.

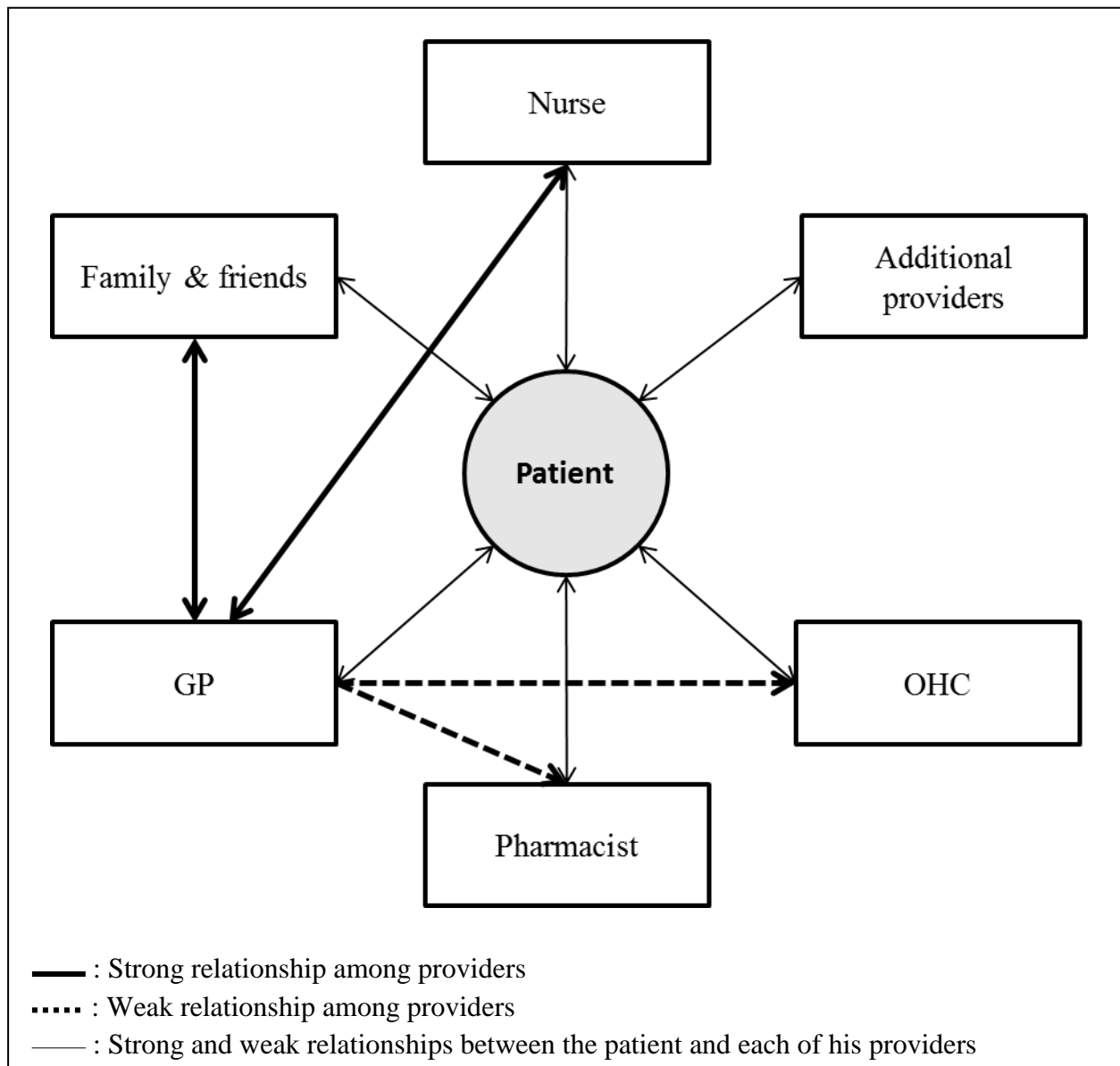
5.5. Discussion

This study maps out the SDN across the patient journey and specifically zooms in on the role of the OHC in the service system.

We apply coordination theory in an attempt to capture the complexity of the SDN (Malone & Crowston, 1990). Several actors are identified in the SDN who each have their specific role in supporting interdependencies that facilitate the roll-out of activities. The GP and asthma nurse are the focal agents in the patient's SDN and work in close collaboration, or even adopt a complementary approach. While the *GP* uses his expert knowledge to establish a correct diagnosis and prescribe effective treatment, the *asthma nurse* adopts a more humane approach. She takes her time to comfort patients which facilitates diagnosis activities and provides additional information and emotional support during treatment. Next to the asthma nurse, *family and friends* are an important source of support during all activities in the journey. Moreover, during pre-diagnosis these actors play a vital role in symptom recognition and encouraging the patient to search professional help (Andersen et al., 2010; Khraim & Carey, 2009). For patients diagnosed at an early age, the parents are important support figures in their journey who have a considerable responsibility in fostering treatment adherence (Conn et al., 2005). Hence, the parents attend all appointments with healthcare professionals and collaborate with them in order to facilitate the diagnosis process, establish the most optimal treatment and support their child's self-management plan. Also for adults diagnosed with asthma, there is evidence found of communication between the patient's healthcare provider and family members. Since it is well-established that asthma has a hereditary basis (Leigh & Marley, 2013), patients receive support from their asthmatic family members who attend doctor encounters. There is a weak link in the SDN between the GP and the *OHCs* in the sense that the GP refers his patients to certain communities that he perceives as being reliable and trustworthy. Likewise, between the GP and *pharmacist* there is a weak link through prescription notes, but patients do not report evidence of teamwork. The pharmacist supports the treatment activities by providing additional information and answering questions which reassures the patient in his treatment plan. The GP, as focal healthcare provider, does not collaborate with any *additional providers*. Patients explore these additional services themselves and do not consult their GP. Figure 5-4 provides an overview of

the actors in the SDN and their relationships. Six parties were identified as contributors to the patient journey. The patient has bidirectional relationships with each of his providers while among providers the links are rather dispersed. In this figure strong relationships represent frequent, in-depth and direct interactions between actors, while weak relationships indicate infrequent, cursory and indirect interactions.

Figure 5-4 The asthma patient's service delivery network (SDN)



The role of the OHC in the SDN has been investigated across activities (i.e., pre-diagnosis, diagnosis, treatment and self-management) in the patient journey. Thereby, the patient uses the

OHC for different purposes in each activity. Before diagnosis patients consult OHCs to prepare their doctor visit and therefore search general information about triggers and symptoms of their potential condition which allows them to self-diagnose. The online information from peers is used as input for the patient–doctor encounter and fuels an informed discussion rather than a one-way lecture. Thereby the patients might consult the doctor’s expertise to assess the information found online (Kivits, 2006). The OHC is also a place to receive emotional support which aids in coping with feelings of frustration, loneliness and fear (Eysenbach, 2003). While patients engage in a general search before diagnosis with a focus on symptoms and triggers, after diagnosis they focus on specific information to complement and validate their doctor’s explanation. Thereby, patients highly value the experiential nature of the information and support provided by peers. During treatment, patients consult OHCs to research side-effects and treatment alternatives which empowers them to actively contribute in medical decisions and supports treatment adherence (Camacho et al., 2009). Patients mainly feel in control, however feelings of fear are alleviated by their peer members in the OHC. Finally, during self-management patients consult the OHC when their condition aggravates and consequently to vent their frustration. Thereby, peers in the OHC aid by suggesting additional routines or by stimulating patients in attending regular check-ups with the asthma nurse to revise medication.

By establishing a research community to probe patients’ experience with OHCs, we were able to observe participant behavior as it would naturally occur in an OHC. For example, by probing into participants’ emotions during diagnosis, one participant on a minimum wage mentioned the frustration he felt caused by the fact that inhaler prescriptions are not for free. Thereby, another participant displayed helping behavior by mentioning the existence of a prescription prepayment card. Hence, the participants answer to questions regarding pre-defined themes, but also raise their personal challenges and thereby behave as they would in their OHC. Furthermore, the outcomes of the automated content analysis confirm the findings of the manual content analysis which generated a more complete understanding of the role of OHCs in the patient’s SDN across his journey.

5.6. Managerial Implications

In order to create satisfying patient experiences, managers and policy makers need to understand which service providers are part of the SDN and what role the OHC plays in this system. The current study identified distinct roles for traditional healthcare providers, the OHC and additional providers which entail important implications for healthcare organizations and OHC managers.

GPs employ a factual, straightforward approach during the consultation, thereby carefully guarding the time spend with each patient. This frustrates many patients and might cause non-adherence to the prescribed treatment (Kerse et al., 2004). Therefore, a close collaboration between the GP and asthma nurse is necessary in order to balance the factual information with more in-depth information and emotional support. Next to the GP and asthma nurse, patients perceive the pharmacist as an integral part of their SDN and recognize his role as information provider which reassures them in their treatment plan. This might indicate potential for stronger integration of the pharmacist in asthma management programs (Armour et al., 2007). Currently, these programs are mainly delivered by the GP in collaboration with the asthma nurse (Mehuys et al., 2008). However the pharmacist's expertise on medication and his frequent contact with the patient on prescription refill could make a useful contribution. Assigning the pharmacist a formal role in the asthma program might facilitate collaboration between healthcare professionals and provides opportunities to coordinate their service delivery. Next to information from experts, patients need testimonies and practical tips from peers in order cope with their condition (Kivits, 2006). The GP and asthma nurse should recognize this need and refer patients to trusted online communities. Thereby, the patients' actions in the OHC should not be ignored by the experts, but rather embraced and integrated in the service delivery. Patients might feel uncomfortable with overtly mentioning their use of OHCs as they fear negative reactions from their professionals (Kivits, 2006). By actively probing patients' use of online information sources such as OHCs professionals might get a better understanding of the patient's existing knowledge base. This allows them to guide patients in their information search, aid them in interpreting online facts and tailor the information provision during the consultation.

Not all patients are empowered enough to independently join an OHC, hence some might need guidance from a professional. The asthma nurse plays an important role in supporting the patient

throughout diagnosis, treatment and self-management. Hence, patients refer to her as a friend, who understands them and takes time. Likewise, the pharmacist helps patients with information about medication and general disease questions during the treatment and self-management activities, thereby fulfilling a vital supporting role in the patient's SDN. These key players in the patient's network should be approached by OHC managers to fulfil a bridging function between the patient's offline SDN and the OHCs. However, next to guiding patients to an OHC, the nurse and pharmacist might play an active role as moderators in the community. In doing so, they might foster patients' trust in the community content which might stimulate the patients' participation level (Leimeister et al., 2005).

Additional service providers such as yoga instructors and personal trainers provide a feeling of control and assurance, however the patient adds them to the SDN without letting his healthcare professionals know. Thereby, vital opportunities for collaboration and integrated service delivery are omitted. Imagine for example the potential of a collaboration between an asthma nurse and yoga teacher on incorporating specific breathing exercise in the yoga routine. Hence, policy makers should invest in developing centralized online medical records which might facilitate collaboration among various members of the SDN and improve service delivery.

5.7. Limitations and Further Research

OHCs are a vital part of the patient's SDN, however the current research contains some limitations that might guide future research. The authors focused on the role of OHCs in the SDN by mapping out the patient journey and consequently adopting a patient perspective. However it might be interesting to confront the service providers identified in this research with the increasingly important role of OHCs and investigate how they adapt and coordinate their activities in an attempt to provide integrated services. Furthermore, the authors selected asthma as a research setting since the management of a chronic disease demands a complex service system involving multiple providers and activities. The majority of patients in our sample suffered from intermittent to moderate asthma, which mirrors the actual disease severity in the asthma population (Asthma UK, 2015b). However, the journey of patients suffering from severe asthma might be different, containing encounters with specialists in hospital (e.g., pulmonologists) rather than merely GPs. Therefore, future research might compare the patient journey among chronic

patients experiencing distinct disease severity and examine the potential differences in the SDN and consequently in the role of the OHC. Likewise, selecting the UK as a research setting for this study introduces country-specific elements of the British healthcare system. For example, in the UK, the asthma nurse role plays a vital role throughout the entire journey as support figure and information provider. There exists a strong relationship between the nurse and GP since the nurse's office is oftentimes located at the GP's medical practice. Finally, despite rigorous attempts to construct a general patient journey, this research contains details that are specific to the asthma context. Hence, continued research should include several chronic conditions to validate these results.

Chapter 6 Conclusions

6.1. General Conclusion

This dissertation investigated value co-creation in online health communities (OHCs). In order to understand the very nature of OHCs and their role in the overall service delivery network regarding value co-creation for patients, I have chosen a multi-level approach by focusing on: (1) the community, (2) the posting, and, (3) the individual patient. Finally, on a more aggregated level I integrate the insights from these previous studies into the overall service delivery network. More specifically, I have applied four complementary research designs which aid in studying the complex phenomenon of value co-creation in OHCs. On the level of the community (Chapter 2), I explore the diversity in OHCs by combining qualitative (i.e., netnography) and quantitative (i.e., principal component and cluster analysis) research techniques. Specifically, I distinguish four community configurations with distinct features that determine their value co-creation. On the level of the postings (Chapter 3) a quantitative approach (i.e., text mining) is used to zoom in on the impact of the patient's reference frame in online postings on cognitive and affective value co-creation. On an individual level (Chapter 4) social network analysis is applied to investigate the influence of a patient's network position on his value co-creation potential. In doing so, a scale is developed and validated in order to measure the items that community members use in assessing the level of cognitive and affective related value. On the overall, aggregated level (Chapter 5) manual and automated content analysis are applied to determine the role of the OHC in the patient's service delivery network.

This final chapter provides an overview of the four studies' main findings and their contributions to existing literature. Additionally, I provide suggestions for further research, based on the challenges I encountered in the research designs that were applied. Further, practical recommendations for managers in the healthcare industry are discussed.

6.1.1. Impact of Community Features on Value Creation in an OHC

Many healthcare organizations struggle with the implementation of digital services such as OHCs (Bain & Co., 2012; McKinsey & Co., 2014). The diverse needs of different patients prevent the set-up of a single, one-size-fits-all community; rather, cognitive and affective related value in a community depends on who participates (e.g., patients, doctors, industry experts), the foundation of their relationship (e.g., trust, reciprocity), and their activities (e.g., sharing experiences, assessing new ideas, recommending alternative treatments). Hence, the

complexity of digital services, which involve various processes of interaction among different actors, demands a more fine-grained view of value co-creation in online communities (Chandler & Lusch, 2015). Furthermore, cognitive and affective value are key dimensions of patients' knowledge (Apeso-Varano et al., 2011; De Valck et al., 2001), but research on their simultaneity in healthcare is scarce. My first study, chapter 2, answered this call for research by conceptualizing and empirically accounting for heterogeneity in OHCs. Hereby four illustrative clusters were defined that reflect the key components of coordination theory: basic information provider, advanced patient knowledge aggregator, systematic networked innovator, and uncomplicated idea sharer. Furthermore this study shed light on the relationship between cognitive and affective value co-creation by stating that cognitive related value might be a necessary condition for affective related value co-creation.

6.1.2. The Patient's Reference Frame as a Driver for Value Co-creation on a Posting Level

Chapter 2 identified cognitive and affective value co-creation as important goals of OHCs, but scant research investigates what drives the nature of the value created (Zhao et al., 2015). In my third chapter I adopted an information processing perspective as a driver of value co-creation on the level of the posting. This study provided evidence that the patient's reference frame constitutes a processing mechanism of information in OHCs and thus affects his online postings and consequently the nature of the value created. Thereby I identified distinct roles for the healthcare professional in sustaining the online information quality and the OHC in providing affective related value.

6.1.3. Structural Network Position as a Driver for Value Co-creation on an Individual Level

The third study, chapter 4, probed into the role of the patient's network position as a driver for cognitive and affective value co-creation. Hence a patients' network position (i.e. connectedness and integration) might have impact on their access to knowledgeable, supportive peers and consequently affect the nature of the value they co-create in the OHC. In doing so, a scale was developed to assess the nature of the value co-creation. In analyzing data collected in three OHCs, I showed that to ensure cognitive and affective related value co-creation, members should be highly connected, but poorly integrated in their network.

6.1.4. The Role of OHCs in the Patient's Service Delivery Network

The first three studies enrich existing literature by looking at the drivers of value co-creation in OHCs. However, OHCs are not used in isolation, but rather in the context of a network of supportive relationships that surround the patient (Tax et al., 2013). Therefore, this final study investigates the role of the OHC in the patient's service delivery network (SDN) and this across the patient journey. As such it aggregates and integrates our insights of the first three studies. This study allowed me to demonstrate the active role that OHCs play in the SDN. Indeed, coordination theory allowed me to identify six actors in the patient's SDN (i.e., GP, nurse, pharmacist, OHC, family & friends and additional service providers) who each play a distinct role in every step of the patient journey. Thereby, the SDN is a loosely coupled network since the providers are connected with the patient, but not necessary with each other. Evidence of a strong link is found between the GP, nurse and friends & family. Additionally, the links between the GP, pharmacist and OHC are weak. Hence, this study provides recommendations on how to foster the collaboration among the members of the SDN since this is a vital prerequisite for delivering an integrated service that raises patient satisfaction (Morgan & Yoder, 2012).

6.2. Theoretical Contributions

First, despite the increased occurrence of value co-creation through means of OHCs, this phenomenon remains significantly under-theorized in current literature (Zhao et al., 2015). Yet, an increased interest from practice in how OHCs can be managed to support value co-creation among patients, motivated me to investigate this phenomenon in-depth (Bain & Co., 2012; McKinsey & Co., 2014). The central premise in this dissertation is the view that patient-to-patient interaction in OHCs is an appropriate context for value co-creation (Zhao et al., 2015). I contribute to current literature on healthcare co-creation (Frost & Massagli, 2008; Nambisan & Nambisan, 2009; Ouschan et al., 2000), and demonstrate that in an OHC context two distinct types of value co-creation emerge that each demand other steering mechanisms.

Second, an increasing number of healthcare organizations are redefining and reestablishing their position in the OHC landscape, hence a multitude of communities is emerging, each with their own distinct features (Bessant & Maher, 2009). This dissertation aims to conceptualize and empirically account for the heterogeneity in OHCs. In doing so, research in digital service provision is advanced by adopting a multidisciplinary approach. Through the

combination of literature on coordination theory (Chronister et al., 2006), service (Vargo & Lusch, 2004b), and knowledge creation (Nonaka, 1994), a fine-grained picture of the components of OHCs is provided. Additionally, this dissertation contributes to the ongoing debate regarding the synergistic or conflicting nature of value dimensions by showing that cognitive related value might be a necessary condition for affective related value co-creation (Apeso-Varano et al., 2011; De Valck et al., 2001). Capturing this dual nature in value co-creation advances research on coordination theory which has focused on cognitive value (e.g.: Edgington et al., 2010; Janssen & Bodemer, 2013; Purohit et al., 2014), but often omitted emotional value.

Third, this dissertation answers a call for more research regarding peer-to-peer sharing of information in online communities (Stokburger-Sauer & Wiertz, 2015) by investigating the impact of the patient's reference frame during online posting on the nature of value co-creation. Thereby, the integration of service marketing theory (i.e., value co-creation) with social psychology (i.e., self versus other) (Duval & Wicklund, 1972) creates new insights regarding how information is being processed and hence translated in cognitive and affective related value. This dissertation also enriches previous research on online communities by examining the effects of community experience thereby capturing a potential dynamic in information processing. While prior research on online communities has suggested effects of experience on group cohesion (Ludwig et al., 2014) and performance (Postmes et al., 1998), I contrast both argumentations and disentangle the effects depending on a patient's reference frame.

Fourth, this dissertation contributes to literature concerning social network theory in OHCs. Previous research demonstrates that an individual's network position (i.e., connectedness and integration) has an impact on value co-creation, but mainly focuses on cognitive value such as information distribution and knowledge sharing (Kleijnen et al., 2009; Reagans & McEvily, 2003). However, networks may also serve as a source of more affective oriented value co-creation which affects customer's attitudes (Loane & D'Alessandro, 2013b). Hereby, an individual's connectedness and integration in the network might have a differential impact on cognitive versus affective value co-creation. The current dissertation opposes this premise as it shows that cognitive as well as affective related value co-creation is fostered by highly connected, but poorly integrated community members. In doing so, I develop and validate a scale that captures cognitive and affective related value in OHCs. Previous research in OHCs

attempted to categorize community content, however without quantifying the nature of the value created (Loane & D'Alessandro, 2013a). This prevents future research to empirically investigate the link between the nature of online value co-creation and several health-related outcome variables such as stress, mental health, quality of life and patient adherence (Cohen & Wills, 1985; Kawachi & Berkman, 2001; Leung & Lee, 2005; Mo & Coulson, 2010). This dissertation advances research regarding value co-creation in the context of healthcare services by defining and measuring the items that community members use in assessing the level of cognitive and affective related value co-creation.

Fifth, this dissertation contributes to the emergent literature stream on OHC integration in the healthcare service system (Laing et al., 2011; Oliver, 2008). Few attempts have been made to expand a previous narrow focus on the processes within the OHC, to a more broad perspective on the service system in which the OHC is embedded (Laing et al., 2011; Oliver, 2008). Existing studies mainly focus on how the patient integrates services from the OHC with the service from one service provider, mainly the healthcare professional (Fang et al., 2008; Keeling et al., 2015). However, patients typically consult multiple service providers in their journey for improved health (Tax et al., 2013). These providers form a network centered on the patient, termed the service delivery network (SDN). The interactions with various providers are embedded in a series of exchanges that may extend over a considerable period of time (Patrício et al., 2011; Zomerdijk & Voss, 2010). Hence, by applying the framework of the patient journey this dissertation is able to capture the evolution of the SDN across each step in the disease. In conclusion, this dissertation advances existing research by conceptualizing the OHC as part of the patient's SDN and thereby focuses on its role across each step of the disease journey.

6.3. Methodological Contributions

The four studies presented in this dissertation approach the phenomenon of value co-creation in OHCs from a different perspective which asks for separate research designs and hence diverse methodologies. Thereby, several methodological contributions are made.

The online context confronts researchers with new types of data which provide challenges for data gathering and analysis. Hence, a netnographic approach is followed which offers a more naturalistic and unobtrusive way to gather sensitive information from patients and hence provides more valid results (Kozinets, 2002). By combining the qualitative oriented method

of netnography with innovative analysis techniques such as text mining, this dissertation overcomes some of the weaknesses of studies that solely rely on one method (Jick, 1979). Netnography implies that researchers use existing, public online data (Kozinets, 2007), hence this might limit research opportunities since the researcher is not able to exert control over the research environment. Therefore, in the final study of this dissertation (Chapter 5) an online focus group is set up in order to directly probe participants' experiences with OHCs. In doing so, I go beyond traditional online focus groups by mimicking the context of an OHC. Consequently, my research instrument stays as close as possible to the setting of our research topic. This allows me to observe participant behavior as it would naturally occur in an OHC (Kozinets, 2002, 2010).

This dissertation focuses on different units of analysis (i.e., community, posting, individual) and different analysis techniques to provide a triangulation of analysis methods. In chapter 2, I focus on the community level as unit of analysis and thereby use categorical principal components analysis (CATPCA) which combines qualitative and quantitative techniques (Jick, 1979, Odekerken-Schröder, et al., 2010). Hence, I started with a qualitative, in-depth analysis of online communities, before contrasting these insights with existing literature and developing a coding scheme to differentiate among communities. By applying this coding scheme across relevant communities, I quantify my insights, detect similarities and differences, and map clusters of communities in a two-dimensional space. Similar approaches have proven helpful in studying heterogeneous patterns in complex research phenomena (Moeller et al., 2013; Odekerken-Schröder et al., 2010). Chapter 3 applies text mining as an innovative way to assess the variables under examination on a posting level. Text mining allows me to capture the nature of the value co-creation in an unobtrusive way. Furthermore, patients are unaware of the reference frame they use during information processing; however, they express this frame in the linguistic features of their online postings. Hence, this dissertation demonstrates that text mining is an adequate way to probe into patients' unconscious information processing activities. Next, data is analyzed by means of seemingly unrelated regression (SUR) since this technique provides more efficient estimates than ordinary least squares in the case of correlated error terms in multiple equation systems (Zellner, 1963). In chapter 4, UCINET VI, the statistical package for social network analysis was used to extract the network measures (Borgatti et al., 2002). Thereby, we focus on the individual community member as unit of analysis. Furthermore a scale development procedure was followed to assess cognitive and affective value co-creation in OHCs. By

doing so, this dissertation addresses the call of the MSI on how to measure customers' perceptions of value (Marketing Science Institute, 2014). Given the extreme skewness in the obtained data which could not be solved by transformation as suggested by Hair (2010), crosstabs were used to provide an answer to the hypotheses formulated (Janssens et al., 2008). In chapter 5, data is gathered via an online focus group, hence to analyze this vast amount of text data I applied a systematic qualitative approach as formulated by Corbin & Strauss (2008). This approach was then complemented with an automated content analysis tool (i.e., Leximancer) which allows data visualization (Rooney, 2005). Hence through this triangulation, I complement the findings from manual content analysis with automated insights which provides a more complete understanding of the research topic.

6.4. Managerial Implications

An increasing number of healthcare organizations move towards digital service delivery, yet struggle with the implementation and management of OHCs (Deloitte, 2014). The studies presented in this dissertation provide managers with recommendations on how to manage and steer value co-creation in OHCs.

First, to successfully implement digital services, value-based segmentation is required, so companies need a good understanding of what drives the value created by their services (McKinsey & Co., 2014). This dissertation provides a clear segmentation for OHCs and specifies the activities to create cognitive and affective related value. The framework presented in the first study (Chapter 2) grants community managers a good overview of the activities that they might implement to achieve the community's goals. Because cognitive related value is a necessary condition for affective related value in OHCs, community managers should strongly encourage the exchange of factual information, advice, and guidance. Practically, this translates into the provision of articles and blogs written by healthcare professionals which may trigger discussions among community members. However, when sufficient trust is established, social and emotional relationships can develop, which in turn support the exchange of affective value. The community host can foster affective related value co-creation by assigning a moderator who can ask specific questions during online conversations and probe participants' emotions. Giving patients a place to tell their 'disease story' also increases knowledge among their peers about their background and previous experiences. In turn, it becomes easier for those peers to empathize with fellow participants and respond in an affective way.

Second, this dissertation suggests that managers need to be aware that a patient's reference frame functions as the underlying mechanism for information processing (Reed, 2002). Hence, patients enter the community with information about their individual situation derived from their doctor encounter which is then shared in online postings through referring to their own situation, i.e. self-referencing. Yet, the community context fosters patients to focus their attention on others and respond to their peers' postings, thereby contributing value through referring to others' situation, i.e. other-referencing. Thereby, self- and other-referencing has a differential impact on value co-creation in OHCs. This suggests that OHCs might be constructed as complementary services to the traditional patient–physician encounter. Healthcare professionals are restricted in time and budget and thereby cannot satisfactorily meet the patient's need for emotional support and additional information (Hoch & Ferguson, 2005; Johnson & Ambrose, 2006). The dissertation shows the potential of OHCs to identify and address unmet patient needs (e.g., need for emotional support and additional information), but also the critical role healthcare professionals may play in affecting the information in the OHCs through traditional healthcare encounters. As such physicians might play a more active role in briefing and informing their patients in a much more structured and specific way comprising not only verbal clarifications, but also factual support provided by them through brochures, digital references, self-management tools etc.

Third, by investigating the patient's social network position as a driver for value co-creation in OHCs, this dissertation demonstrates that highly connected, but poorly integrated network members contribute more in terms of cognitive and affective value. In practice, managers should foster patients' connectedness while weakening their integration. This can be achieved by providing a large number of community threads around topics that are appealing to many members. By doing so, the discussion that emerges around each topic will contain a high number of individuals which increases the connectedness of each individual who contributes to the thread. Furthermore, the presence of a large number of threads can foster participants to contribute in multiple discussions and hence weakens their integration. Additionally, intrinsic rewarding systems such as recognition for their contributions (e.g., a badge or mention on the home page) affect members' self-esteem and consequently their activity level (Wasko & Faraj, 2005). Increased activity means contributing to several threads which increases the member's connectedness and weakens his integration. Furthermore, by presenting a scale to measure cognitive and affective value this dissertation provides OHC managers with an instrument to conceptualize the value created in their community. The scale

allows them to build automatic monitoring systems which apply text mining to examine the evolution of cognitive and affective value in the community and thereby track the community's health. Hence, excessive cognitive value with limited affective value or reversed might indicate a problem which needs to be adjusted by the community manager.

Finally, this dissertation shows that OHCs do not operate in isolation, but are embedded in the patient's service delivery network (SDN). In order to create satisfying patient experiences, managers need to understand which service providers are part of the SDN and what role the OHC plays in this system. Currently, disease (i.e., asthma) management programs are mainly delivered by the GP in collaboration with a nurse (Mehuys et al., 2008). However, this dissertation detects an important role for the pharmacist given his expertise on medication and his frequent contact with the patient. Hence by assigning the pharmacist a formal role in the disease program collaboration between healthcare professionals might be facilitated which provides opportunities to coordinate their service delivery and thereby promote improved health outcomes. Furthermore, the OHC is an important actor in the patient's SDN. Hence, traditional service providers should not ignore the patients' actions in the OHC, but rather embrace them and integrate them in the service delivery. Patients might feel uncomfortable with overtly mentioning their use of OHCs as they fear negative reactions from their professionals (Kivits, 2006). By actively probing patients' use of online information sources such as OHCs professionals might get a better understanding of the patient's existing knowledge base. This allows them to guide patients in their information search, aid them in interpreting online facts and tailor the information provision during the consultation. However, not all patients are empowered enough to independently join an OHC, hence some might need guidance from a professional. This dissertation reveals that patients assign important roles to the pharmacist and nurse in their SDN. Consequently, these key players in the patient's network should be approached by OHC managers to fulfil a bridging function between the patient's offline SDN and the OHC. However, next to guiding patients to an OHC, the nurse and pharmacist might play an active role as moderators in the community. In doing so, they might foster patients' trust in the community content which might stimulate the patients' participation level (Leimeister et al., 2005).

6.5. Limitations and Suggestions for Further Research

The research designs from the studies presented in this dissertation introduce some limitations which might be fruitful paths for further research.

First, throughout this dissertation I focus on patient-centered communities, with limited interference from professionals or other stakeholders, so it might be interesting to investigate professional-oriented communities. Previous research indicates that physician networks are characterized by overspending (Hammerschmidt et al., 2012); online professional communities might help cut costs for end consumers and patients. Investigating how the key components of coordination theory emerge and how professional communities deal with their inherent conflicts could provide strong potential for improving resource utilization patterns.

Second, in this dissertation the drivers of value co-creation in OHCs are investigated on a posting level. Obviously there exists a chronological order between the online postings which means that each post recapitulates more or less previous postings. Digging deeper into contribution dynamics within a discussion thread might provide insight into how online value co-creation builds up and develops over time. Therefore, future studies could examine different discussion threads focusing on how the conversation develops by input of other members, on what point the discussion ends and for what reason.

Third, as explained in the previous limitation, online value co-creation develops over time. Therefore, next to recognizing the dynamics in the discussion threads, the dynamic nature of the OHC as a whole should be investigated. Over time network members join or leave the community, their network position might change or their behavior in the community might be altered due to increased community and disease experience (Lewis et al., 2008). Furthermore, in this dissertation, I omit to differentiate between the type of OHC member such as ‘answer people’, ‘question people’ and ‘discussion starters’ (Hansen et al., 2010). However, discussion starters might guide the content of the conversation and thereby influence the cognitive and affective related value co-creation. By taking this into account, future research might provide insights in the relationship between member type, structural network position and value co-creation potential. Therefore, future research should take into account the dynamic aspects of the community and its members while investigating the nature of value co-creation in OHCs.

Appendices

Appendix A

Summary of online health communities investigated (Chapter 2)

ID	Name	Link	Health topic	Years
1	CarePages	https://www.carepages.com/	General	15
2	What To Expect	http://www.whattoexpect.com	Specific: pregnancy	18
3	Locate a Doc	http://www.locateadoc.com/	Specific: plastic surgery	17
4	Psychcentral	www.psychcentral.com	Specific: mental health	24
5	Spark People	http://www.sparkpeople.com/	General	14
6	Spine Universe	http://www.spineuniverse.com/	Specific: spine conditions	16
7	23andme	https://www.23andme.com	Specific: DNA testing	9
8	Diabetic Connect	http://www.diabeticconnect.com	Specific: diabetes	9
9	Dokter	http://www.dokter.nl	General	10
10	E-health Forum	http://ehealthforum.com	General	12
11	Gezondheid	http://www.gezondheid.be	General	4
12	Health Boards	http://www.healthboards.com	General	17
13	HealthMap	www.healthmap.org	General	9
14	Flunearyou	https://flunearyou.org	Specific: flu	4
15	Medwatcher	https://medwatcher.org	General	5
16	HealthTap	https://www.healthtap.com	General	5
17	Healthy Place	http://www.healthyplace.com/	General	15
18	I hadcancer	www.ihadcancer.com	Specific: cancer	4
19	Inspire	http://www.inspire.com/	General	10
20	MDJunction	www.mdjunction.com	General	9
21	Medhelp	http://www.medhelp.org	General	21
22	Medisch Forum	http://medischforum.nl/	General	11
23	MedWonders	http://medwonders.com/	General	14
24	MumsNet	www.mumsnet.com	specific: pregnancy	15
25	NetDoctor	www.netdoctor.co.uk	General	7
26	NHS Choices	www.nhs.uk	General	18
27	Patient Opinion	https://www.patientopinion.org.uk	General	10
28	Patientslikeme	www.patientslikeme.com	General	11
29	Propeller Health	http://propellerhealth.com/	Specific: asthma and COPD	5
30	Rate My Hospital	http://www.ratemyhospital.ie/	General	9
31	Sugarstats	www.sugarstats.com	Specific: diabetes	9
32	The Body	www.thebody.com	Specific: AIDS/HIV	20
33	Tudiabetes	www.tudiabetes.org	Specific: diabetes	8
34	Vlaamse Liga tegen kanker	http://forum.tegenkanker.be/	Specific: cancer	10
35	WebMD	www.webmd.com	General	19
36	Germtrax	http://www.germtrax.com/	General	3
37	ZocDoc	www.zocdoc.com	General	8
38	Whatnext	www.whatnext.com	Specific: cancer	4
39	Treato	www.treato.com	General	8
40	Sixpartwater	www.sixpartwater.org	General	8
41	Hearingjourney	http://hearingjourney.com/	Specific: Cochlear implants	9
42	Myglu	https://myglu.org/	Specific: diabetes	5
43	Patient.co.uk	http://www.patient.co.uk/	General	18
44	Patient Innovation	https://patient-innovation.com/	General	1
45	Soberrecovery	http://www.soberrecovery.com/	Specific: drug rehabilitation	15
46	The gooddrugsguide	http://www.thegooddrugsguide.com/	Specific: drug rehabilitation	14
47	Allaboutcounseling	http://www.allaboutcounseling.com/	Specific: counseling	17
48	Onehealth	http://www.onehealth.com/	General	5
49	Smartpatients	https://www.smartpatients.com/	General	5
50	Crohnology	https://crohnology.com/	Specific: Crohn's and colitis	7

Appendix B

Scale development: An overview of the interview respondents (Chapter 4)

	Initials	Age	Gender	Condition	Role	Duration
1	IP	37	M	Cancer	Patient	108 minutes
2	MV	58	F	Cancer	Patient	45 minutes
3	R VdB	56	F	Cancer	Patient	55 minutes
4	LR	61	M	Cancer	Patient	24 minutes
5	LC	51	M	Cancer	Patient	161 minutes
6	MH	45	F	Cancer & ALS	Patient	41 minutes
7	M VdB	35	F	Cancer	Patient	48 minutes
8	LW	31	F	Cancer	Patient	28 minutes
9	VG	41	F	ALS	Patient (caregiver)	120 minutes
10	LW	27	M	Stoma	Moderator	60 minutes
11	EM	47	M	Stoma	Moderator	90 minutes
12	IG	64	F	Diabetes	Moderator	44 minutes
13	RP	45	F	Cancer	Moderator	98 minutes

Appendix C

Stimuli classification survey (Chapter 4)

Support in online health communities consists of an informational and an emotional component. In the tables on these following 4 pages, we would like you to: (1) indicate whether you recognize the item from your online participation, and (2) indicate whether the item belongs to cure or care. Cure relates to cognitive, informational support. Hence, all the information that helps you to cure. Care relates to affective, emotional support. Hence, all the information that helps in emotional coping with your condition.

	Do you recognize this item in the online context?		How would you classify this item?	
	Yes (1)	No (2)	Cure (i.e., informational) (1)	Care (i.e., emotional) (2)
(1) We discuss doctors and hospitals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(2) We encourage each other to ask questions to doctors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(3) We discuss potential causes of our disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(4) We prepare each other for future events/next steps in the disease process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(5) We share information from third parties (newspaper, magazine, online)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(6) We compare our disease situation with each other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(7) We receive confirmation from each other regarding side effects etc.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(8) We help each other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(9) We aid each other in keeping our feet on the ground and putting things in perspective	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(10) We can share our fears	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(11) We discuss treatments and medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(12) We can share our nervous feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(13) We receive recognition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(14) We can share feelings of bitterness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(15) We can ventilate feelings of stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(16) We discuss symptoms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(17) We can talk about family who does not understand our situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(18) We can share feelings of empathy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(19) We can share affection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Do you recognize this item in the online context?		How would you classify this item?	
	Yes (1)	No (2)	Cure (i.e., informational) (1)	Care (i.e., emotional) (2)
(20) There is mutual understanding among us	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(21) We discuss devices and material	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(22) We share good news	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(23) We can tell our disease story	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(24) We receive support from each other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(25) We can share sadness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(26) We can share physical pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(27) We exchange practical tips	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(28) We give and receive advice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(29) We exchange experiences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(30) We discuss the process of accepting our disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(31) We talk about our family, partner, children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(32) We create a bond among each other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(33) We build friendship online	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(34) Participating in the community feels cosy, like a social gathering	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(35) We invigorate each other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(36) We give pep-talks to each other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(37) We share bad news	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(38) There is room for humor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix D

Stimuli item purification and selection survey (Chapter 4)

On the next 16 pages, you find examples of postings from an online health community. We provide you with a scale where you can indicate the extent to which you agree that the message includes certain information.

Online message 1 “I have been on several meds in the last 2 years. (Keppra, Trileptal, Topamax, and currently Lamictal/Lamotrigine). I had memory loss problems with the Topamax so I stopped taking it and changed to Lamictal.” This online message includes...

Online message 2 “I had an attack (Blah) and had school. I’m not sure which is worse! Haha.” This online message includes...

Online message 3 “You are a kindred spirit, Mary!! Thank you so much for sharing here!” This online message includes...

Online message 4 “Thank you, my support friends!” This online message includes...

Online message 5 “But then I think of all the people who have it so much worse.” This online message includes...

Online message 6 “I’ve never been a person who got headaches or sick very often so this is very frustrating for me.” This online message includes...

Online message 7 “I’ve had seizures a few times when I’ve been asleep.” This online message includes...

Online message 8 “I’m sorry to hear that, I hope you’re feeling better soon.” This online message includes...

Online message 9 “I was diagnosed several years ago with classic migraine, as well as migraines.” This online message includes...

Online message 10 “Dr Andres Kanner is a triple board certified epi, psych, and neurophysiologist who is among tops in the field and has some good things to say about this topic.” This online message includes...

Online message 11 “My parents swear that flashing lights to this day cause my seizures.” This online message includes...

Online message 12 “I saw your message and I know just how you feel.” This online message includes...

Online message 13 “I’ve had similar attacks triggered by stress.” This online message includes...

Online message 14 “God bless you.” This online message includes...

Online message 15 “Never give up. Life is too good to stop living!” This online message includes...

Online message 16 “I thought you might like to read some of Joe's entries on his blog. He's been diagnosed with Alzheimer's since 2007 and has been featured in some documentaries about the disease.” This online message includes...

The 16 messages above were coded by the participants on following scale:

	Strongly disagree (1)	Disagree (2)	Somewhat disagree (3)	Neither agree or disagree (8)	Somewhat agree (9)	Agree (7)	Strongly agree (6)
(1) Sharing information on treatments and medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(2) Compliments.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(3) Sharing information on symptoms.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(4) Sympathy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(5) Sharing information about doctors and hospitals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(6) Sharing information on causes of the disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(7) Prayer and blessing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(8) Encouragement.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(9) Sharing information on external sources such as doctors, newspaper, magazine and online sources.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(10) Empathy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(11) Reassessment of one's own situation compared to others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(12) Confirmation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(13) Sharing information on diagnosis.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(14) Feelings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(15) Evidence of community feelings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(16) Humor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix E

Crosstabs (Chapter 4)

Dataset 1: MSA

Cure 1 & Connectedness

		Connectedness	
		<i>Low</i>	<i>High</i>
Cure 1	<i>Low</i>	30 48.4%	24 47.1%
	<i>High</i>	32 51.6%	27 52.9%
$\chi^2=0.020$ (p=1.000) <i>Exact Sig. (2-sided)</i>		62 100%	51 100%

Cure 1 & Integration

		Integration	
		<i>Low</i>	<i>High</i>
Cure 1	<i>Low</i>	23 40.4%	31 55.4%
	<i>High</i>	34 59.6%	25 44.6%
$\chi^2=2.549$ (p=0.133) <i>Exact Sig. (2-sided)</i>		57 100%	56 100%

Cure 2 & Connectedness

		Connectedness	
		<i>Low</i>	<i>High</i>
Cure 2	<i>Low</i>	50 80.6%	15 29.4%
	<i>High</i>	12 19.4%	36 70.6%
$\chi^2=30.060$ (p=0.000) <i>Exact Sig. (2-sided)</i>		62 100%	51 100%

Cure 2 & Integration

		Integration	
		Low	High
Cure 2	Low	27 47.4%	38 67.9%
	High	30 52.6%	18 32.1%
$\chi^2=4.853$ (p=0.036) Exact Sig. (2-sided)		57 100%	56 100%

Care 1 & Connectedness

		Connectedness	
		Low	High
Care 1	Low	53 85.5%	22 43.1%
	High	9 14.5%	29 56.9%
$\chi^2=22.482$ (p=0.000) Exact Sig. (2-sided)		62 100%	51 100%

Care 1 & Integration

		Integration	
		Low	High
Care 1	Low	29 50.9%	46 82.1%
	High	28 49.1%	10 17.9%
$\chi^2=12.372$ (p=0.001) Exact Sig. (2-sided)		57 100%	56 100%

Care 2 & Connectedness

		Connectedness	
		<i>Low</i>	<i>High</i>
Care 2	<i>Low</i>	50 80.6%	21 41.2%
	<i>High</i>	12 19.4%	30 58.8%
$\chi^2=18.665$ (p=0.000) <i>Exact Sig. (2-sided)</i>		62 100%	51 100%

Care 2 & Integration

		Integration	
		<i>Low</i>	<i>High</i>
Care 2	<i>Low</i>	27 47.4%	44 78.6%
	<i>High</i>	30 52.6%	12 21.4%
$\chi^2=11.777$ (p=0.001) <i>Exact Sig. (2-sided)</i>		57 100%	56 100%

Dataset 2: Epilepsy

Cure 1 & Connectedness

		Connectedness	
		<i>Low</i>	<i>High</i>
Cure 1	<i>Low</i>	30 44.1%	37 56.1%
	<i>High</i>	38 55.9%	29 43.9%
$\chi^2=2.521$ (p=0.226) <i>Exact Sig. (2-sided)</i>		68 100%	66 100%

Cure 1 & Integration

		Integration	
		<i>Low</i>	<i>High</i>
Cure 1	<i>Low</i>	24 49.0%	43 50.6%
	<i>High</i>	25 51.0%	42 49.4%
$\chi^2=3.658$ (p=1.000) <i>Exact Sig. (2-sided)</i>		49 100%	85 100%

Cure 2 & Connectedness

		Connectedness	
		<i>Low</i>	<i>High</i>
Cure 2	<i>Low</i>	49 72.1%	18 27.3%
	<i>High</i>	19 27.9%	48 72.7%
$\chi^2=26.872$ (p=0.000) <i>Exact Sig. (2-sided)</i>		68 100%	66 100%

Cure 2 & Integration

		Integration	
		<i>Low</i>	<i>High</i>
Cure 2	<i>Low</i>	3 6.1%	64 75.3%
	<i>High</i>	46 93.9%	21 24.7%
$\chi^2=25.281$ (p=0.000) <i>Exact Sig. (2-sided)</i>		49 100%	85 100%

Care 1 & Connectedness

		Connectedness	
		<i>Low</i>	<i>High</i>
Care 1	<i>Low</i>	55 80.9%	28 42.4%
	<i>High</i>	13 19.1%	38 57.6%
$\chi^2=21.013$ (p=0.000) <i>Exact Sig. (2-sided)</i>		68 100%	66 100%

Care 1 & Integration

		Integration	
		<i>Low</i>	<i>High</i>
Care 1	<i>Low</i>	27 40.3%	56 83.6%
	<i>High</i>	40 59.7%	11 16.4%
$\chi^2=26.623$ (p=0.000) <i>Exact Sig. (2-sided)</i>		67 100%	66 100%

Care 2 & Connectedness

		Connectedness	
		<i>Low</i>	<i>High</i>
Care 2	<i>Low</i>	59 86.8%	28 42.4%
	<i>High</i>	9 13.2%	38 57.6%
$\chi^2=28.916$ (p=0.000) <i>Exact Sig. (2-sided)</i>		68 100%	66 100%

Care 2 & Integration

		Integration	
		Low	High
Care 2	Low	28 41.8%	59 88.1%
	High	39 58.2%	8 11.9%
$\chi^2=31.493$ (p=0.000) Exact Sig. (2-sided)		67 100%	67 100%

Dataset 3: Neurobrain

Cure 1 & Connectedness

		Connectedness	
		Low	High
Cure 1	Low	59 43.1%	55 66.3%
	High	78 56.9%	28 33.7%
$\chi^2=15.892$ (p=0.001) Exact Sig. (2-sided)		137 100%	83 100%

Cure 1 & Integration

		Integration	
		Low	High
Cure 1	Low	43 55.1%	71 50.0%
	High	35 44.9%	71 50.0%
$\chi^2=3.526$ (p=0.484) Exact Sig. (2-sided)		78 100%	142 100%

Cure 2 & Connectedness

		Connectedness	
		<i>Low</i>	<i>High</i>
Cure 2	<i>Low</i>	89 65.0%	33 39.8%
	<i>High</i>	48 35.0%	50 60.2%
$\chi^2=13.292$ (p=0.000) <i>Exact Sig. (2-sided)</i>		137 100%	83 100%

Cure 2 & Integration

		Integration	
		<i>Low</i>	<i>High</i>
Cure 2	<i>Low</i>	14 17.9%	108 76.1%
	<i>High</i>	64 82.1%	34 23.9%
$\chi^2=68.815$ (p=0.000) <i>Exact Sig. (2-sided)</i>		78 100%	142 100%

Care 1 & Connectedness

		Connectedness	
		<i>Low</i>	<i>High</i>
Care 1	<i>Low</i>	86 62.8%	35 42.2%
	<i>High</i>	51 37.2%	48 57.8%
$\chi^2=8.866$ (p=0.003) <i>Exact Sig. (2-sided)</i>		137 100%	83 100%

Care 1 & Integration

		Integration	
		Low	High
Care 1	Low	14 17.9%	107 75.4%
	High	64 82.1%	35 24.6%
$\chi^2=67.029$ (p=0.000) Exact Sig. (2-sided)		78 100%	142 100%

Care 2 & Connectedness

		Connectedness	
		Low	High
Care 2	Low	77 56.2%	33 39.8%
	High	60 43.8%	50 60.2%
$\chi^2=5.591$ (p=0.026) Exact Sig. (2-sided)		137 100%	83 100%

Care 2 & Integration

		Integration	
		Low	High
Care 2	Low	11 14.1%	99 69.7%
	High	67 85.9%	43 30.3%
$\chi^2=62.290$ (p=0.000) Exact Sig. (2-sided)		78 100%	142 100%

Appendix F

Example of a discussion in the research community (Chapter 5)

Asthma Journey

 SarahVO ▼
Admin

Asthma Journey

Home
Members
My Page
News

🔍 Share your emotions regarding your asthma diagnosis

Hello!

The diagnosis of asthma might evoke an emotional roller-coaster. Let us go back to those days to explore your feelings.

- Can you describe how you felt **before** you received the actual diagnosis and experienced the first symptoms?
- How did you feel when you received the **diagnosis** of asthma?

For example:

"Before my diagnosis I felt frustrated since all the coughing, sneezing and shortness of breath limited me in my daily activities. Not knowing what was going on made me anxious. But afterwards, it was a good feeling to know that I had a diagnosis and, because it was specific, it was helpful for me. But at the same time it was sad, knowing that it's a chronic condition that I am still in denial about. There are a lot of questions I have so in a sense I feel worse since the diagnosis."

Thank you for sharing!

Sarah

Community Manager

Sarah Van Oerle

Hi, I'm moderator Sarah. I'm very curious to hear all your asthma stories! Let's talk!

moderator.sarah@insitescommunities.com

Recently

Cat10 posted I don't remember feeling particularly troubled with breathing...

🕒 13w

Marymod posted Before being diagnosed with Asthma, I felt rather frustrated as I had...

🕒 13w

marylou52 posted I was diagnosed at the age of 14 (I am now 34). I remember being...

🕒 13w

jennyocat posted I can't remember as I would have been so young but my older brother...

🕒 14w

KatjaStout posted To be honest I'm not really sure about before but I know that when I...

🕒 14w



Neptune

It can get stressful and annoying - mostly because I have memory problems and often forget to take my medication. I mostly talk about this to my partner.

Reply



nikki87

The daily management of asthma is really annoying sometimes with having to make sure I have enough medication in the house to cover me, in the summer and winter I get really bad so can go through quite a few inhalers, so I'm constantly checking how much I have and ordering extras.

If I have to order extras other than what's on my repeat I get the reception staff at my doctors questioning as to why I'm ordering more which really gets to me, it has nothing to do with them and my life can be at risk without them, they think they know more than me yet can't even say the names of my inhalers, so just proves how much they know.

Reply



anpa25

it is frustrating to me a bit, as on any given day, the first thing I have to think about is make sure I take my inhaler with me. It's a bit annoying, but it's much better than not having it with me.

I share my emotions mainly with my family, but will also share it with whoever is with me at the time.

Reply



mrblooby

I find the self medication side of Asthma a breeze. I don't get too worked up about it as it is just a fact of life - I'm going to be stuck with it until either it just goes or a medical breakthrough is found. If I am having issues with my asthma I will usually talk with my Wife, but I try not to bore her with it too much as I'm able to cope with it on my own. I'm pretty good with management of my inhalers, so don't have any issues with that either. My inhaler comes with me everywhere and I rarely leave it at home - It's a part of me.

Reply



G-owen

the self management as of now is quite simple, but when I first got it was a little tricky and annoying. I don't really show any emotions towards it really as it's just normal to me I've had it so long now over 20 years so doesn't bother me.

If anything ever happens I always have the support from friends and family

Reply



Danson16

I think it can be very distressing, stressful, upsetting and annoying all at the same time. On good days I feel quite proud I'm managing, other days I feel upset and down-trodden. It's hard to predict your emotions each day when dealing with my asthma.

Reply

**Saraj**

Having to make sure you have enough medication can be a real pain and fighting to get a prescription and having it processed by the chemist can also be difficult, frustrating and expensive! I also feel that it's unfair as many medical conditions have free prescriptions, but not asthma, and it can be life threatening. It's just one of the many things you have to accept and get on with, life as an asthmatic!

Reply

**spike**

I agree and as a minimum wage earner it seems a little unfair I am paying out quite a bit monthly for my inhalers to keep me just about healthy enough to work

Reply

**Saraj**

You can get a 3 month or 12 month Prescription prepayment card which helps. I tend to get a 3 month one which is about £27 and then get all my allowed prescriptions in that 3 month period at approx. £24 for each prescription this saves me a great deal of money.

Reply

**spike**

Thanks for this Sarah that's helpful

Reply

**madmax**

Thankfully I live in Wales and I get my prescription free. I currently have to have 20 tablets and 3 inhalers prescribed so it would be really expensive if I had to pay.

Reply

**spike**

Yeah Max I can imagine it is expensive for me..

Reply

**toxcity02**

My asthma has improved as I've got older. I've had asthma for as long as I can remember so the management side is kind of normal to me. I only really struggle if I've got a cold. My mum is a nurse so she is great to ask for advice especially as she helped manage my asthma as a small child. Occasionally I'll have a vent on asthma forums, but I am mindful that I don't have it anywhere near as bad as a lot of people so I'm thankful for that.

Reply

**emmalouise**

it can be stressing and gets me down at times. i talk about it to my family who also suffer with asthma and my partner

Reply



clare.e.mckenzie

I find it quite embarrassing in the office when the air co kicks in, my asthma really kicks in. I am constantly making excuses. It is frustrating, tiring and annoying. My inhalers make very little difference. The only thing that will help is moving to a hotter climate. I know that works as I lived in the Caribbean for 2 years. Unfortunately I am back in the UK.

♡ 0 Reply



spike

It is difficult especially with nearly being sick every time I take my inhalers and share this with my partner. Stress is a huge trigger and let few years have been through enormous stress with divorce losing ng kids changing jobs moving etc and my asthma has been significantly worse.. I have found this forum helpful and hope it may continue in one form or another.

♡ 0 Reply



helen000

I generally feel ok with my day to day management. I've had asthma for a long time so I come to terms with the day to day workings of my condition. It can get frustrating at times when I get a flare up and especially in the summer months when the pollen count is high as its meant to be a time to go outdoors and enjoy the nice weather etc but doing an outdoor activity with my children can sometimes be hard work.

I share my emotions with my family they are really understanding and can be my rock when things are bad as they stick with me when i'm in a bad mood! Sharing online is also helpful when I talk to other sufferers as they have more first hand understanding and can vent a bit more knowing they understand the condition more.

♡ 0 Reply



Katsz79

I think the only thing I emotions I feel is annoyed because, to me, some of my other medical problems are much more complicated and difficult to manage. So asthma is pretty easy for me. I just know to keep my inhaler on standby and to ensure I have other allergy relief. I think it's also important to keep on top of dust and animal hair, so I do vacuum regularly, especially in my bedroom. My emotions are also kind of contained because of my medication for bipolar. I have had asthma since I was a young child, so it's just something i've learned to live with really.

I would normally discuss this with my mum because she is asthmatic, but not diagnosed until later in life, so, if for example, if I am feeling a bit wheezy, then I would ask my mum if she is experiencing the same problem, especially now that there is a lot of humidity. We can compare if it is an individual problem or if we are both experiencing the same problem.

♡ 0 Reply



mickyxxx

I have a good support in my family who often lend a ear when I'm worried. I get worried if I've left the house without my inhalers incase I have an attack and I worry when my medication is running low incase I don't get an appointment in time at the doctors.

♡ 0 Reply

Appendix G

Overview of topics and questions (Chapter 5)

Step	Topic	Questions
	General asthma coping	<ul style="list-style-type: none"> • In which OHCs do you participate? • How did you found your OHC(s)? • Why did you become member of an OHC? • What are the most important benefits of participation in an OHC? • How does participation in online health community facilitate your life with asthma? • How does searching information and support online facilitate your life with asthma? • Imagine the last 5 online messages you posted in your favorite health community. Briefly tell us what they were about. • What do you do to cope with your condition? • With whom do you talk to vent your feelings?
Diagnosis	Patient journey	<p>How did your diagnosing process look like? Please describe your disease story from the first symptoms to the actual diagnosis, thereby answering following questions:</p> <ul style="list-style-type: none"> • What kind of healthcare providers did you have to meet to receive the diagnosis of asthma? • How did you get in touch with them? (<i>e.g.: referral from GP, word-of-mouth</i>) • What activities did you undertake with your healthcare providers to establish a diagnosis? (<i>e.g.: tests</i>)
	Emotions	<ul style="list-style-type: none"> • Can you describe how you felt before you received the actual diagnosis and experienced the first symptoms? • How did you feel when you received the diagnosis of asthma?
	Role of OHCs	<ul style="list-style-type: none"> • Can you describe a specific event that triggered you to participate in an OHC during the diagnosis stage? • How did the participation in the community help you in the diagnosing process? • How did your participation in the community had an impact on your encounters with healthcare providers during the diagnosis stage?
Treatment	Patient journey	<ul style="list-style-type: none"> • What kind of different treatments did you receive up to now? • What kind of healthcare providers did you meet to establish this treatment?

		<ul style="list-style-type: none"> • How did you get in touch with them? • What activities did you undertake with your healthcare providers to establish the correct treatment? • How did you experience the process of establishing the right treatment for your case?
	Emotions	<p>Let us go back to the day that you created and discussed your treatment plan with your doctor.</p> <ul style="list-style-type: none"> • How did you feel back then? • Can you describe those emotions?
	Role of OHCs	<ul style="list-style-type: none"> • Can you describe a specific event that triggered you to participate in an OHC during treatment? • Can you give a concrete example of how your OHC participation has an impact on your treatment decisions? • Can you give a concrete example of how your OHC participation has an impact on your treatment adherence? • How did your participation in the community had an impact on your encounters with healthcare providers during the treatment stage?
Self-management	Patient journey	<ul style="list-style-type: none"> • Imagine a typical day in your life: what do you have to do every day to keep your asthma under control? • What kind of healthcare providers do you consult to help you with your self-management? • Do you also consult other providers that help you to keep your asthma under control?
	Emotions	<ul style="list-style-type: none"> • What kind of emotions do you feel during the self-management of your disease? • With whom do you share your emotions?
	Role of OHCs	<ul style="list-style-type: none"> • Can you describe a specific event that triggered you to participate in an OHC during self-management? • Can you give a concrete example of how your OHC participation has an impact on your self-management? • How did your participation in the community had an impact on your encounters with healthcare providers during the self-management stage?

Note: Projective techniques are omitted from this representation.

Dutch Summary

Het huidige gezondheidssysteem staat onder druk door een vergrijzing van de bevolking en een simultane toename in chronische ziekten. Deze tendens doet de kosten betreffende gezondheidszorg stijgen en stimuleert steeds meer bedrijven om op zoek te gaan naar innovatieve en kostenefficiënte manieren om hun diensten te verstrekken. Online gezondheidsplatformen zijn daarbij aan een opmars bezig als een aanvullend systeem voor de traditionele dienstverlening. In deze platformen kunnen patiënten hun ervaringen betreffende hun ziekte delen met anderen, van elkaar leren of emotionele steun uitwisselen. Door informatie betreffende behandelingen en medicatie te delen, spelen zij in op elkaars nood aan het begrijpen van hun ziekte en wordt er cognitieve waarde gecreëerd. Anderzijds wordt er emotionele steun gedeeld. Zo wordt ingespeeld op de nood aan empathie van patiënten, en bijgevolg affectieve waarde gecreëerd. Deze cognitieve en affectieve waardecreatie helpt patiënten in het omgaan met hun ziekte.

In de marketing literatuur zien we een toename van studies rond online gezondheidsplatformen waarin zowel antecedenten, processen en gevolgen worden onderzocht. Verder wordt er ook veel aandacht besteed aan het belang van co-creatie voor de gezondheidszorg in zijn geheel. Ondanks deze inspanningen bemerken we dat er weinig onderzoek wordt verricht naar hoe co-creatie plaats vindt in de context van online gezondheidsplatformen. Deze doctoraats thesis geeft een aanzet om deze lacune in te vullen door de co-creatie van cognitieve en affectieve waarde in online gezondheidsplatformen te bestuderen. Gezien de complexe aard van dit fenomeen werden er verschillende literatuurstromen geïntegreerd, alsook verschillende onderzoeksopzetten ontwikkeld.

In een eerste studie gebruiken we coördinatie theorie om patronen in online gezondheidsplatformen te onderzoeken. De vier componenten van coördinatie theorie (i.e., doelen, activiteiten, actoren en ondersteunende mechanismen) worden toegepast op een steekproef van 50 platformen wat ons toelaat om overeenkomsten en verschillen te onderzoeken. Door principale componenten analyse en cluster analyse te combineren, identificeren we vier afzonderlijke platformconfiguraties. De analyses onthullen verschillen in het niveau van cognitieve en affectieve waardecreatie, soorten activiteiten, de betrokken actoren, alsook de mate waarin platformleden hun gegevens openbaar maken. Er werden vier verschillende platformconfiguraties gevonden: fundamentele informatieverancier, geavanceerde kenniskoppelaar, systematisch geconnecteerde innovator, en ongecompliceerde ideeëndeler. De

specifieke kenmerken van deze gezondheidsplatformen bepalen hun vermogen om kennis te internaliseren en te externaliseren, wat uiteindelijk ook de aard van hun waardecreatie zal bepalen.

In de tweede studie van deze doctoraatsthesis focussen we op de kenmerken van online boodschappen in gezondheidsplatformen. Specifiek onderzoeken we hierbij het referentiekader (i.e., zelf versus ander) van de patiënt. Dit bepaalt de manier waarop de patiënt informatie verwerkt en bijgevolg ook de aard van de waardecreatie (i.e., cognitief en affectief) in online gezondheidsplatformen. De bevindingen tonen aan dat informatie die verzameld wordt tijdens het doktersbezoek en verwerkt wordt via ‘referenties naar zichzelf’, cognitieve waardecreatie stimuleert, maar affectieve waardecreatie beperkt. ‘Referenties naar anderen’ doet juist het tegenovergestelde door cognitieve waardecreatie te reduceren terwijl het affectieve waardecreatie bevordert. De ervaring die een patiënt heeft met het platform (i.e., het aantal verzonden boodschappen) speelt een cruciale rol, aangezien dit de impact van ‘referenties naar zichzelf en anderen’ op cognitieve en affectieve waardecreatie modereert. Algemeen tonen deze bevindingen aan dat online gezondheidsplatformen een belangrijke rol spelen in het identificeren van en het tegemoet komen aan onvervulde noden van patiënten (vb.: de nood aan emotionele steun en bijkomende informatie). Verder tonen we ook aan dat medische deskundigen een kritieke rol vervullen in het beïnvloeden van de online informatiestroom via traditionele doktersbezoeken.

In de derde studie passen we een sociaal netwerk perspectief toe om te begrijpen hoe waarde gecreëerd wordt in online gezondheidsplatformen. De netwerkpositie (i.e., connectiviteit en integratie) van de patiënt beïnvloedt zijn gedrag en bijgevolg ook zijn mogelijkheden om waarde te creëren. De hypothesen in deze studie worden getest op data verzameld in drie gezondheidsplatformen. Deze bevatten 467 leden die in totaal 1534 online boodschappen hebben gepost. Voor dit onderzoek werd er een schaal ontwikkeld en gevalideerd om cognitieve en affectieve waardecreatie te meten. De bevindingen tonen aan dat met name sterk geconnecteerde maar zwak geïntegreerde leden de cognitieve en affectieve waarde co-creatie in online gezondheidsplatformen bevorderen.

In de laatste studie van deze doctoraatsthesis onderzoeken we het netwerk van dienstverleners dat de patiënt omringt en in het bijzonder de rol van online gezondheidsplatformen in dit dienstverleningsnetwerk. Er wordt een online onderzoeksplatform opgezet om 124 patiënten te

bevragen over hun ervaring met verscheidene dienstverleners tijdens verschillende stappen in hun ziekteproces. Coördinatie theorie wordt daarbij gebruikt als theoretisch kader om het dienstverleningsnetwerk te bestuderen en de rol van online platformen daarbinnen te bepalen. De kwalitatieve data wordt geanalyseerd door een combinatie van kwalitatieve en kwantitatieve inhoudsanalyse wat ons toestaat om tekst data te visualiseren. De bevindingen suggereren een essentiële rol voor gezondheidsplatformen doorheen verschillende stappen in het ziekteproces en identificeren allerlei mogelijkheden op het gebied van coördinatie en samenwerking in het dienstverleningsnetwerk.

In zijn geheel draagt deze doctoraatsthesis bij aan een beter begrip van waardecreatie in online gezondheidsplatformen. Hierbij wordt eerst een beeld geschetst van de diversiteit in online gezondheidsplatformen en bijgevolg worden er verschillende platformconfiguraties voorgesteld. Verder toont deze thesis aan welke invloed de eigenschappen van online boodschappen en individuele kenmerken hebben op cognitieve en affectieve waardecreatie. Uiteindelijk wordt ook gekeken naar hoe online gezondheidsplatformen ingebed zijn in de patiënt zijn omringende netwerk van dienstverleners. Deze thesis levert dan ook diverse theoretische en methodologische bijdragen aan academische literatuur die tot aanbevelingen voor het bedrijfsleven leiden.

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