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How patients use multiple information sources to fulfill their social support needs

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R. SANDERS

ACTIVELY CONVERGING

How patients use multiple information sources
to fulfill their social support needs

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How patients use multiple information sources
to fulfill their social support needs

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Colofon

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Amsterdam 2021

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ACTIVELY CONVERGING

How patients use multiple information sources to fulfill their social support needs

ACADEMISCH PROEFSCHRIFT

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aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
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ten overstaan van een door het College voor Promoties ingestelde commissie,
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Table of Contents

CHAPTER 1	Introduction	7
CHAPTER 2	Different Platforms for Different Patients' Needs: Automatic Content Analysis of Different Online Health Information Platforms	15
CHAPTER 3	Patients' Convergence of Mass and Interpersonal Communication on an Online Forum: Hybrid Methods Analysis	39
CHAPTER 4	A Mixed Method Study Investigating the Impact of Talking about Patients' Internet Use on Patient- Reported Outcomes	63
CHAPTER 5	Summary	82
	Discussion	85
ADDENDUM	References	98
	Nederlandse Samenvatting	109
	Dankwoord	114
	Author Contributions	121

1

CHAPTER 1

Introduction

In this chapter, I will give a brief introduction of the most important aspects of the current thesis. A brief outline will place the concepts central to this dissertation into a broader perspective. This dissertation investigates what social support needs patients seek to fulfil by combining multiple media sources (i.e., convergence), how these social support needs influence online health information use, and the effects of convergence on patient outcomes (satisfaction, recall, and medication adherence). To investigate this, we must consider the changes to both the broader sociological position of the patient and the media landscape in which this patient operates. Therefore, I will first discuss the sociological paradigm shift, followed by the changes in the media landscape. Then, I will briefly discuss patients' social support needs and how, through convergence, these social support needs can be fulfilled. I end with a discussion of the new tools that are available to study these concepts.

The Changing Paradigm of the Patient

Over the coming decade, the incidence of cancer will increase to 22.200.000 people worldwide (Li et al., 2020). This makes cancer the second most common disease (Bray et al., 2018; WHO, 2018). Modern medicine can treat cancer increasingly better. Therefore, currently, many types of cancer are considered chronic diseases. When diagnosed with cancer, patients have to handle many questions such as “What is cancer?” and “What is the chance of survival?”. Besides, patients also need to handle considerable amounts of uncertainty and fear, resulting in concerns such as “How do I tell my loved ones?”. For these social support needs, patients have a plethora of sources of information at their disposal, including online health information.

The reliance on online health information by patients can be placed in a larger sociological trend. In 1986, the birth year of the writer of this dissertation, the term *risk society* was coined by Ulrich Beck to reflect the period called second or reflexive modernity (Beck, 1992). Here, the influence of central powers (e.g., the government and church) and institutions diminished. Information and authority were critically examined, and uncertainties were raised regarding the different aspects of life that were assumed to be true, including the roles of medical experts. Doctors' knowledge was no longer accepted as the only source of information. Additional knowledge became accessible to laypersons via different media. As a consequence, the roles of laypersons changed, and they became reflexive actors in modern society. Reflexive actors are active in their pursuit of self-improvement, so they take an active role in managing their diseases, information provision, and treatment. In short, this reflexive self, acts in a calculated manner to achieve self-improvement and is sceptical about expert knowledge. Doctors became, in theory, means to an end. In this capacity, parallels can be drawn between the reflexive self

and the notion of a patient as a consumer. Consumerism assumes that laypersons act as rational actors in the context of medical consultations. Both the reflexive actor and the patient as a consumer “are understood as actively calculating, assessing and, if necessary, countering expert knowledge and autonomy with the objective of maximizing the value of services such as health care” (Lupton, 1997, p. 137). Therefore, health care continues to become a commodity in which many patients are active and autonomous. While the degree to which patients truly aim to achieve a pure consumerism relationship with a medical expert can be questioned, and so can be the degree to which health care can be deconstructed as a pure rational event, without any doubt, information provision, the role of the medical expert, and the relationship between a patient and a provider has changed in the last decades due to a more active role of the patient. Patients take an increasingly active role in managing their diseases by acquiring information outside of doctors’ offices (Abdul-Muhsin, Tyson, Raghu, & Humphreys, 2015; Sherif, Pluye, Thoër, & Rodriguez, 2018).

Online Health Information in a Broader Media Landscape

The outlined paradigm change was supported and accelerated by the arrival of the internet. The internet made it possible for laypersons to access information at any time, at no cost, and from the comfort of one’s own home (Cline & Haynes, 2001; Powell, Inglis, Ronnie, & Large, 2011). As a result, in many Western countries, such as the Netherlands and the United States, the internet has become the largest source of health-related information (Sherif et al., 2018; van de Belt et al., 2013). Due to the easy access to online health information, the traditional knowledge gap between a patient and a medical expert decreased; and the consultation, the patient-provider relationship, and patient outcomes are likely to change as a result (Bylund, Guegue, D’Agostino, Imes, & Sonet, 2009; Hong, Peña-Purcell, & Ory, 2012; Osei-Frimpong, Wilson, & Lemke, 2018; Shen et al., 2015; Wang, Ashvetiya, Quaye, Parakh, & Martin, 2018).

Although the literature outlines barriers to effective online health information use that patients might encounter, such as difficulty finding quality information (Gray et al., 2005; Cline & Haynes, 2001), research suggests that vast access to online health information and support has the potential to contribute to patients’ autonomous role and wellbeing: patients who searched for online health information reported feeling more empowered during the consultation and making more informed health decisions (Chen, & Aslani, 2018; Sherif et al., 2018; Sommerhalder, Abraham, Zufferey, Barth, & Abel, 2009; Tan & Goonawardene, 2017).

Patient Social Support Needs

The use of online health information can be linked to the social support needs of patients. Cancer patients encounter many cognitive and affective needs (hereafter called “social support needs” unless otherwise specified) (Bensing & Verhaak, 2004). Patients, to varying degrees, have the need to know and understand the following questions: What is cancer? What is the likelihood of being cured? What medicines are available? These are a few examples of the cognitive needs of patients. The affective needs of patients are just as important. Patients also wish to feel acknowledged and understood (Bensing & Verhaak, 2004). Patients could ask themselves whether they are alone in their situation, how fellow patients handle certain side effects or how a fellow patient solved similar problems. With the rise of the internet, multiple platforms became available to fulfil these social support needs. However, in much of the research, these platforms are not distinguished from each other, treating online health information or the internet as umbrella terms. Therefore, knowledge is lacking on which content fulfils which social support needs. For example, patients can use validated websites such as *thuisarts.nl* or medical libraries on websites such as *kanker.nl* to fulfil their cognitive needs. In the Netherlands, the website *kanker.nl* is the largest cancer-related website. In December 2020, this site attracted almost 900.000 visitors and more than 607.000 unique visitors, and reached 1.8 million page views. This website provides both expert-generated platforms such as a medical library and peer-generated platforms such as forums and blogs. On these platforms, patients can asynchronously communicate with fellow patients. Fellow patients can relate to each other and share experiences. In this way, patients feel less isolated and better understood (Moorhead et al., 2013; van Udenkraan et al., 2008). Insight into which content fulfils which social support needs is important because online health information has the potential to “set the agenda” for future behaviour.

New Tools to Study Patients’ Social Support Needs and Convergence Online

Online health information provides patients with both peer- and expert-generated platforms. It is expected that patients use a combination of these platforms to fulfil their social support needs. For example, a patient who validates the information received from a medical library by asking questions on a forum. This process is called convergence. Convergence can be defined as a sequence of mass and/or interpersonal communication channel usage to fulfil the user’s (new) social support needs (Sanders, Araujo, Vliegthart, van Eenbergen, van Weert, & Linn, 2020). Convergence can entail both online and offline sources. For example, a patient can write a blog post about their experiences during

a consultation with a medical expert or post a question on a forum to ask for clarification on the information received from a medical expert (intermedium convergence).

Regardless of whether convergence occurs solely between online sources or a combination of online or offline sources, traces of convergence are often visible online. Because many patients now share information online with fellow patients, increasingly more data are becoming available (van Atteveld & Peng, 2018). For example, on blogs and forums, writers include references to other media they have used, details about their current (health) situation, and their motives for writing. In these blogs or on these forums, people also report their experiences with their treatment or their medical expert. The therapeutic effect of writing, and the positive effect on those who read it has been empirically confirmed (e.g., Laing, Moules, Estefan, Lang, 2017; Scaletti & Hocking, 2010). Additionally, this data can give researchers a glance into the writers' world. Activities such as writing a blog post about one's situation or opening a forum thread to inquire about experiences provide data that can help to understand how patients fulfil their social support needs online. New analytical tools are available from computational social science and enable health communication researchers to understand and systematically analyse processes such as convergence by analysing naturally occurring data originating from forums (e.g., Chen, Li, Liang, & Tsai, 2018; van Atteveld & Peng, 2018). We can now use these methods to better understand, for example, what patients do online, what social support needs are addressed by the content available, and how online sources differ in the social support needs they address. We can also use these data to study convergence by examining references to other sources of information and studying the subsequent effects on patients' online behaviour. Within this dissertation, this type of data will be gathered and analysed to answer the first and second questions of the thesis: 1) *what social support needs do cancer patients address when using online health information, and how does the online health information provided on different platforms relate to those social support needs;* and 2) *what is the frequency of convergence and what are the signs of convergence, motives for posting, and social support needs that can be detected online?* The data originating from *kanker.nl* will be the main data source for answering these questions.

Convergence in the Context of the Medical Consultation

Besides online health information, medical experts are still considered an important source of information. In fact, online health information and medical experts are the two most important and most often used sources of information for patients (Huisman, 2021). The use of a combination of mass and interpersonal sources has the potential to positively impact how patients manage their health and, consequently, health care (Powel, Darvell, & Gray, 2003). Patients who read up before a consultation arrive in the consultation room with some basic understanding of their disease. This is expected to enhance their information processing (through, for example, forward encoding, Voorveld,

Neijens, & Smit, 2011). Discussing online health information with medical experts is expected to stimulate the co-creation of understanding, aid information recall, and increase shared decision making (Nguyen et al., 2019; Osei-Frimpong et al., 2018; Tan & Goonawardene, 2017).

Thus, this dissertation assumes that both sources (i.e., online health information and medical experts) influence each other through convergence. Convergence in turn is expected to influence communication during consultation and patient outcomes. By studying online health information in the context of a consultation, the third and final question of this dissertation can be answered: 3) *what are the effects of convergence on patient outcomes (i.e., satisfaction with a consultation, the recall of medical information, and medication adherence)?*

Dissertation Outline

To answer the questions raised, three studies will be conducted. Figure 1 shows the (relations between the) concepts that are studied in the different empirical chapters of this dissertation.

Chapter 2

In the second chapter, I start by specifying the umbrella term “online health information”. To this end, I will explore how different online health information platforms relate to previously identified patients’ social support needs. It is important to understand which social support needs patients have and how the content available online can fulfil those social support needs. To gain insight into this, I explore the differences in the content between peer- and expert-generated online health information platforms and link the online topics to a theoretical model in which different social support needs are identified. I do so to gain a better understanding of how online platforms relate to patients’ social support needs.

Chapter 3

In Chapter 3, I investigate convergence. This concept places patients’ use of online health information platforms in the context of different mass media and interpersonal sources of information such as medical experts, fellow patients, and other online health information platforms. Examples include how patients use the information of an interpersonal conversation with a medical expert to gather more information online (intermedium convergence) or how patients use two different medical library entries to fulfil their needs (intramedium convergence). In this chapter, I aim to gain insight into the frequency of

reported signs of convergence, how convergence affects what posters write online, the motives for posting, and the social support needs posters seek to fulfil.

Chapter 4

In Chapter 4, I investigate online health information-seeking behaviour in the context of consultations (intermedium convergence). More specifically, I explore the discussion of online health information seeking and relate this to patient outcomes using observational data among a population of chronically ill patients. By analysing transcribed recordings and patient-reported outcomes after consultations, I can explore whether patients and medical experts discuss online health information and whether that discussion impacts patient outcomes.

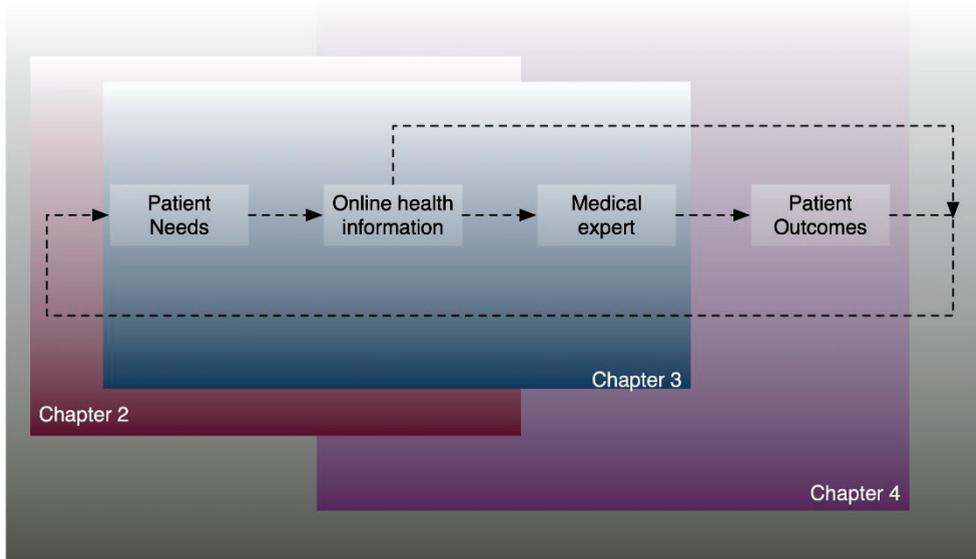


Figure 1. Visual representation of dissertation.

2

CHAPTER 2

Different Platforms for Different Patients' Needs: Automatic Content Analysis of Different Online Health Information Platforms

This chapter is an adapted version of the published article:

Sanders, R., Linn, A. J., Araujo, T. B., Vliegthart, R., van Eenbergen, M. C., & van Weert, J. C. (2020). Different platforms for different patients' needs: Automatic content analysis of different online health information platforms. *International Journal of Human-Computer Studies*, 137, 102386. doi:10.1016/j.ijhcs.2019.102386

Abstract

Prior online health research has mainly focused on the predictors or outcomes of online health information, leaving online health information itself understudied. Therefore, online health information has remained an umbrella term encompassing different platforms (expert- vs. peer-generated). A hybrid method that combines qualitative and computational methods is used to identify different topics discussed on these different platforms, and an initial model of patients' social support needs was developed and applied to data obtained from the hybrid method. Using topic modeling ($N_{posts}=52,990$), topics on two expert- and two peer-generated platforms were identified. Differences between and within platforms were found. While peer-generated platforms mainly covered interaction on emotional support topics, expert-generated platforms covered informational topics. Within peer-generated platforms, patients used their experiences differently.

Introduction

The diagnosis of cancer causes patients and their surroundings a great amount of fear and uncertainty (Leydon et al., 2000; Sanson-Fisher et al., 2000). As a result, cancer patients and their relatives have many questions like “What is cancer?” or “What sort of treatment is available?”. Some of these questions get answered by a medical expert. However, many patients experience unmet cognitive and affective needs during their cancer journey, even after a discussion with a medical expert (hereafter called “social support needs”; Cotten & Gupta, 2004; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Puts, Papoutsis, Springall, & Tourangeau, 2012; Sillence, Briggs, Harris, & Fishwick, 2006; Iconomou, Vagenakis, & Kalofonos, 2001). Acquiring health information online helps patients fulfill these social support needs (Goldsmith, 2004). Currently, up to 70% of chronically ill patients seek online health information (Abdul-Muhsin, Tyson, Raghu, & Humphreys, 2015; Rupert et al., 2016).

Previous research focused either on the predictors or on the outcomes of using online health information (e.g., Cotten & Gupta, 2004; Puts et al., 2012; Sanders & Linn, 2018). However, we lack information on which content, if any, fulfills which social support needs. This information is important to have because online health information has the potential to “set the agenda” for future behavior (Anderson, Rainey, & Eysenbach, 2003; McCombs & Shaw, 1972; Xiao, Sharman, Rao, & Upadhyaya, 2014). A first step is to disentangle the term “online health information”. This term has been used as an umbrella term to describe multiple platforms on the internet such as online blogs, medical libraries, question-and-answer pages, and discussion forums. These different platforms are likely to contain different topics and are expected to fulfill different social support needs (Anderson et al., 2003; Prestin, Vieux, & Chou, 2015). While scholars have advocated for a comparison between these platforms, to the best of our knowledge, no previous studies have investigated if and how content differs on these platforms (Coulson, Buchanan, & Aubeeluck, 2007; Klemm et al., 2003). Because online health information is often unreliable or difficult to understand, patients and medical experts should work together to fulfill patients' social support needs (Rains & Young, 2009; Buis & Whitten, 2011; Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Knowledge about the content of different platforms helps in this regard by deciding which platform to visit to fulfil specific support needs.

Using a hybrid method that combines a literature review and a computational social science method, the current study aims to investigate the differences in content between online health information platforms (Shah, Cappella, & Neuman, 2015). A theoretical model is developed to serve as a *roadmap* to identify emerging topics and gain a better understanding of how online platforms relate to patients' social support needs.

The current study adds to the literature in multiple ways. On a methodological level, this study bridges the gap between computational methods and “classic” social science methods. The current study distinguishes itself by using a theoretical model as a starting point. On a theoretical level, this study integrates the diversity of various social support needs and makes a systematic and holistic analysis of the field of online health information research possible. We will demonstrate the usefulness of using a model of social support needs as a basis for unsupervised machine learning. On a practical level, the results allow us to understand which social support needs patients fulfill online instead of, or in addition to, fulfilling during appointments with a medical expert.

Towards a Model of Social Support Needs

The use of online health information is increasing, and this trend can be placed within a larger societal trend of people taking more control over all aspects of their lives (Beck, Giddens, & Lash, 1994; Lupton, 1997, 2013). Online health information-seeking behavior can be defined as, “... active efforts to obtain specific information in response to a relevant event” (Niederdeppe et al., 2007, p.154). In the current study, “the relevant event” is operationalized as being diagnosed with or living with (someone with) cancer. The “active effort” is operationalized as searching online for social support. A model will be developed that acknowledges that patients go online because of different cognitive and affective needs. In this model, it is assumed that due to these different needs, patients search online to find different forms of social support on a variety of topics. To illustrate, users can fulfill their “abstract” cognitive and affective needs (layer I) by going online to find different forms of social support (layer II) which is provided to them via content covering different topics. The layers of the proposed model go from broad to specific. Previous research shows that patients go through similar phases during their health information seeking process; normally the patient starts with a broad need (e.g., I want to know more about my disease, i.e., cognitive need) and this need becomes more specific through searching and browsing until that specific need is fulfilled (e.g., I want to know more about medicine X; Wilson, Ford, Elis, Foster & Spink, 2002). See table 1 for the proposed model of patients’ social support needs.

Layer I: patients’ needs. The first layer of the framework consists of two basic underlying patients’ needs: *cognitive* and *affective* (Bensing & Verhaak, 2004; Coulson, 2005). Patients have the need to know and understand (i.e., cognitive needs) as well as the need to feel acknowledged and understood (i.e., affective needs). An example of a cognitive need is the need for information about treatment. An affective need can be the need to receive reassurance. This classification is the first layer of the proposed model.

Layer II: social support categories. The cognitive and affective needs specified in layer I can be fulfilled by seeking for and receiving online social support, which is the second

layer of the framework. The Social Support Behavior Code and the Optimal Matching Model (SSBC; Cutrona, 1990; Cutrona & Russell, 1990; Cutrona & Suhr, 1992; House, 1983) provide a useful categorization of how patients' needs can be fulfilled by providing and receiving social support in an online context. Within social support, different categories can be distinguished, namely, *informational support* (fulfilling patients' cognitive needs) and *esteem, network, and emotional support* (fulfilling patients' affective needs). These categories are explained below.

Patients' cognitive needs in layer I can be fulfilled by providing informational support. Informational support means providing guidance to users on topics such as the disease, symptom interpretation, and illness management (Coulson et al., 2007). Rutten et al. (2005) offer a typology that can be used to further specify the social support categories into social support topics that can be measured using topic modeling. This typology is based on a review clustering the support needs of cancer patients about certain health topics or issues. The typology describes nine cognitive informational support topics: *cancer-specific, treatment-related, prognosis, rehabilitation, surveillance and health information, interpersonal/social information, financial/legal information, medical system information, and body image information*. Based on other offline literature *tangible assistance* was added to informational support (Cutrona, 1990). For descriptions of the categories, see Table 1. These informational support categories and topics form the second and third layers of the model.

Rutten et al.'s (2005) only emotional support topic is *coping information*. The subcategories of coping information given by Rutten and colleagues (2005) seem to include all social support categories (e.g., emotional reactions, support from other patients, and spiritual support). Although previous studies show a correlation between the various support concepts, we believe there is also a clear theoretical distinction between network and esteem support and to a lesser degree, emotional support. Therefore, we use the definition of Rutten and colleagues (2005) in which the coping information category specifies the three forms of support. The following distinction is made: the subtopic *coping and spiritual support* reflects esteem support, the subtopic *member interaction* reflects network support, and the subtopic *emotional support* reflects emotional support. Esteem support refers to communicating respect and confidence in one's ability to deal with the disease. Network support entails communicating one's belonging to a group of people sharing the same concerns or (health) complaints. Emotional support refers to messages expressing empathy, love, and caring (Coulson et al., 2007). Rutten's typology can be used to further specify the social support categories *esteem, network, and emotional support* into observable social support topics such as coping, spiritual information, and member interaction. See Table 1 for the complete model and the subtopics descriptions.

Towards Testing the Model of Patients' Social Support Needs

By grouping and combining the previously described layers, the model of patients' social support needs is proposed (see Table 1). This model allows us to measure latent needs and social support categories via observable social support topics. By combining the outcomes of previous studies, covering multiple sources of information, and targeting different (cancer) populations, the model consistently conceptualizes and identifies different types of social support topics within online health information platforms (Buis & Whitten, 2011). This process will contribute to a greater generalizability of research findings in the future. A first step would be to map the content of these different platforms. The results of this first step can then be applied to the proposed model. The following research question is proposed: *What social support topics can be distinguished online on cancer-related platforms, and to what extent do these topics fit within with the model (RQ1)?*

Online Information on Different Platforms

The internet offers the unique capability to integrate various forms of content on different platforms (i.e., patients' blogs, questions and answers, medical libraries, and discussion forums; Anderson et al., 2003). To fulfill patients' social support needs, information is required that "matches" their information needs (Cutrona, 1990). Most research has focused on one platform or its content, mainly social network sites (e.g., Hether, Murphy, & Valente, 2014) or online support groups (e.g., Klemm et al., 2003), or the research did not differentiate between platforms (e.g., Gutierrez, Kindratt, Pagels, Foster, & Gimpel, 2014).

One way of categorizing these different platforms is based on the author of the information (Rupert et al., 2016). The literature recognizes peer-generated (e.g., the author is a fellow patient writing on blogs or discussion forums) and expert-generated information (e.g., the author is a medical expert writing on a (medical) library or answer- and-questions pages by medical experts). Because fellow patients are "uniquely positioned to understand one another in ways that others, including friends or family, may not" (Namkoong et al., 2013, p.170), peer-generated content can provide a description of experiences to which a patient can relate. This situation includes the potential to read about personal experiences with certain treatments, learn practical tips in dealing with side-effects, or exchange emotional support (Hether et al., 2014; Prestin et al., 2015; Rupert et al., 2016; Wang, Kraut, & Levine, 2015). In contrast, expert-generated platforms can provide patients with medically validated, factual information.

While content written by peers and experts can both include social support categories and topics of the proposed model, the extent to which these categories and topics can be found on these platforms is expected to differ. For example, peer-generated platforms are believed to provide higher levels of affective social support categories compared to expert-

Table 1.
Framework of Patients' Social Support Needs

Layer I: Needs	Layer II: Social Support Category	Sublayer Social Support Topic	Description	
Cognitive needs	Informational support	Cancer-specific information	Information about (diagnosis of) cancer, physical effects, test, symptoms.	
		Treatment-related information	Information about available treatments, how treatment works & side effects.	
		Prognosis information	Change of cure, survival expectations, expectations for future health.	
		Rehabilitation information	Self care, nutrition, availability medical supplies for at home	
		Surveillance and health information	Maintaining or restoring physical health after treatment and preventive behaviors.	
		Interpersonal /social information	Effect of disease on relations with family, friends, caregiver, employment, and social life in general.	
		Financial / legal information	Costs associated with disease (e.g., treatment, insurance, writing a testament).	
		Medical system information	Health care system, interactions with health care providers, evaluation of physicians.	
Affective needs	Esteem support	Body image / sexuality information	Sexuality and physical appearance (i.e., attractiveness).	
		Tangible assistance	Providing, or offering to provide, information, goods, and services.	
	Network support	Coping & Spiritual	Communicating respect and confidence in one's abilities to deal with disease (e.g., compliments and validation).	
		Member interaction	Communicating belonging to a group of persons with similar concerns or experiences	
	Emotional support	Emotional support	Emotional support	Communicating love, concern, empathy, expressions of emotions or caring, attentive listening, reassurance

generated platforms (Wang et al., 2015). However, it is unknown how these differences relate to the social support topics discussed. Therefore, the current research will include both peer- and expert-generated platforms to gain a better understanding of the content discussed among these different platforms. This situation leads to the following research question: *How do peer- and expert-generated cancer-related platforms differ from each other in terms of social support topics (RQ2)?*

Method

Data

The current study used data retrieved from Kanker.nl. Kanker.nl is one of the largest and best-known Dutch websites for cancer-related information. The website offers both peer- and expert-generated platforms which users can read and follow as well as respond to. Peer-generated platforms on this website include blogs and discussion groups. On blogs, users can share their stories in multiple blogposts over a longer period of time. Other users can follow their blogposts and comment on them. Discussion groups contain threads about a variety of topics on which users can ask questions, share experiences, and respond to each other. Expert-generated platforms consist of the medical library and expert questions. The medical library gives information on various types of cancer and covers the cancer trajectory from tests and diagnosis until rehabilitation. Expert questions are a mix of peer- (i.e., questions) and expert-generated content (i.e., answers).

The website is well used: in February 2016, Kanker.nl had approximately 390,000 visits. For example, patient blogs had 19,000 unique visitors and 130,000 page views. Discussion groups had 15,500 unique visitors with 50,000 page views per month. The data used in the current study cover the period from April 2013 until November 2016. Since the website is often used and offers both peer- and expert generated platforms, it is a valuable case for the current study.

Users are required to register and must provide their name and a valid e-mail address. An automated e-mail is then sent requiring individuals to confirm their registration by clicking on the registration link. Participants of all platforms within Kanker.nl gave (standard) consent for using their data for research when they registered. Ethical approval for the current study was provided by the ethical committee of the University of Amsterdam: 2016-PC-7547.

Analysis

Topic modeling. Unsupervised computer-assisted content analysis was used to analyze the data without restricting the analysis based on previously defined categories in coding schemes. This technique has several benefits. First, it allows for the analysis of large amounts of data. This method can be used on multiple datasets to compare, unsupervised, the occurrence of topics on different platforms (i.e., without any interference from the researcher). Second, the analysis can be easily replicated by other researchers (Wang et al., 2015).

Latent Dirichlet Allocation (LDA) was used as a topic modeling method using the *Gensim* package (Řehůřek & Sojka, 2010; Blei, Ng, & Jordan, 2003). Topic modeling

is a computer algorithm that identifies latent constructs by word co-occurrence, using word distribution across documents (e.g., individual posts and questions; Jacobi, van Atteveldt, & Welbers, 2016). Based on these documents, topics were created and displayed as clusters of words. These clusters contain the most-used words for each topic (see preprocessing for more information). For each topic, the latent meaning (topic) can be (subjectively) inferred from these words. To derive reliable and interpretable topics, several steps need to be taken within LDA.

Preprocessing. The raw data received from any online source, including the sources used in this study, is “noisy”. Therefore, work needs to be performed before analysis can begin (Petz et al., 2014). Data were preprocessed as follows: First, all *html* mark-up and punctuation was removed (e.g., “” and “ ”). Second, stop words were removed using a custom made Dutch stop word list (e.g., *en* [and], *te* [too] and *eens* [once/ever]). Third, topic modeling was done. This step resulted in a list of top words, whose latent meanings can be regarded as topics. A list of top words per topic is provided, as well as a score that indicates the weighted presence of the top word per topic (topic loading). Based on these top words and Figure 1, the outcome of the topic modeling was evaluated on how meaningful, consistent, and discriminative the identified topics were. Fourth, words in top words deemed unnecessary or uninformative were removed by adjusting the code. For example, in the first and second cycles, all names were replaced by the word *naam* [name] using a custom made list of popular Dutch names. The same procedure was repeated for all forms of cancer, which were replaced by the word *kankervorm* [type of cancer]. This process was used since an individual name or type of cancer was not needed to answer the current research questions. Fifth, because the results of automatic stemming for the Dutch language was too rudimentary (i.e., resulting in uninterpretable and unreadable words), multiple words were grouped together manually by adding this information to the code (e.g., *hooii* and *hallo* became *hoi* [hi]). To limit the influence of the noninformative difference between multiple conjugations of verbs on the topics, verb conjugations were grouped by the verb stem.

Parameters. To run the LDA model, values for the number of expected topics and the *alpha* parameter needed to be determined. Values of 0.10, 0.05, 0.01, 0.005, and 0.001 were tried. In line with the recommendation of Jacobi et al. (2016), a low alpha value was used to obtain fewer topics per document (i.e., $\alpha = 0.001$).

To establish the number of topics, analyses were performed on 5, 10, 15, 20, 25, 30, and 40 topics. For a maximum of 25 topics, the meaning of each topic could be identified without too much overlap between topics. Next, consensus about the meaning of the 25 topics was reached during meetings with the research team.

Differences between platforms. To answer the second research question, for all 25 topics, linear equations from topic modeling were applied to the sample of posts. This process resulted in a score for all 25 topics per document that measured the extent to which these topics occurred within each document. Then, per platform mean topic scores were calculated for all 25 topics. Finally, *MANOVA* was used to gain insight into the differences in the mean topic scores between the platforms. The 25 topics were used as dependent variables and the platforms as independent variables. When the *Levene's F test* showed significant differences between the four platforms, *Bonferroni post hoc tests* were used to gain more insights into these differences.

Results

Data

The post sample size was 52,995. This sample of documents consisted of all blog posts and replies ($n = 22,662$), all forum entries ($n = 9,573$), all expert questions and answers ($n = 16,458$), and all entries into the medical libraries ($n = 4,338$). The average number of words per document for each platforms was $M_{\text{blogs}} = 78.55$ ($SD = 159.89$), $M_{\text{forum}} = 53.03$ ($SD = 64.01$), $M_{\text{questions}} = 41.62$ ($SD = 42.26$), and $M_{\text{library}} = 163.72$ ($SD = 131.47$).

Topic Identification

We wanted to gain insight into which social support topics could be distinguished on different cancer-related platforms of a health website and the extent to which these subtopics fit within the model of social support needs (RQ1). Many of the subtopics identified are similar to the social support topics that are part of the model of patients' social support needs. This similarity means many support needs identified within previous literature on offline information sources exist online. Figure 1 provides a visual representation of the subtopics. Furthermore, the percentages displayed under Figure 1 show the relative proportion of a subtopic in the complete sample of posts (i.e., the dominance of a certain subtopic within the content analyzed). Furthermore, Figure 1 shows several (partly) overlapping subtopics, or subtopics that were similar to each other (i.e., certain words belong to different subtopics). In Table 2, the integration of the subtopics into the model is summarized, and example posts of each subtopic are given. We elaborate on this process below and discuss the social support model by layer to the extent the predefined topics can be identified in the results of our topic model.

Layer II: social support category—informational support. Based on our theoretical model we expected to find topics ranging from cancer-specific information to tangible assistance that could be grouped under this support category (see Table 3). The analysis revealed that several subtopics were grouped under the social support topic *cancer*

specific information, such as cancer tests (subtopic 9) and cancer detection (subtopic 14). Additionally, several subtopics were part of the social support topic *treatment-related information*: cancer treatment information (subtopic 3), side-effects treatment (subtopic 6), other (alternative) treatments (subtopic 19), gastrointestinal treatment (subtopic 21), and treatment consequences (subtopic 23). Thus, when people talk about cancer specific information, they often use words related to for example detection such as lymphedema, carcinoembryonic antigen test [CEA], contrast fluid, etc. When people talk online about treatment-related information, they use words related to cancer treatment information such as type of cancer or treatment(s).

Subtopics covering rehabilitation were found and grouped under the social support topic *rehabilitation information*. These subtopics are rehabilitation (subtopic 10) and after care (subtopic 12). In addition, subtopics covering the social support topic surveillance and health information included nutrition (subtopic 17) and hereditary (subtopic 22). We found that the subtopics emotions and cancer (subtopic 4) and impact cancer (relatives) (subtopic 11) were grouped under the social support topic *interpersonal/social information*. The social support topic financial/legal information included the subtopics insurance/financial (subtopic 15) and employment (subtopic 18). To illustrate, content about rehabilitation information features words like fatigue, recovery, and complaints. However, content included in the subtopic interpersonal/social information featured words such as life, emotions, fear, and feeling.

Within the social support topic medical system information, the following subtopics were found: cancer organizations (subtopic 13), cancer research (subtopic 16), and medical trials (subtopic 20). The social support topic *referral to other information sources* included the topics: information sources (subtopic 24) and external organizations (subtopic 25). In summary, the medical system information contained content around the words such as Dutch Cancer Society [kwf], trail, research, and scientific.

Based on our theoretical model we expected the presence of the social support topics *tangible assistance*, *prognosis information*, and *body image/sexuality information*. However, the results of our topic model included no such subtopics.

Layer II: social support—esteem, network and emotional support. Also for this layer, we investigate the extent to which and how the predefined topics from the social support model could be found in the outcome of the topic model. First, the social support topic *coping and spiritual* was found and included the subtopic affective support (subtopic 7). Furthermore, *support from others and groups* was found and included subtopic member interactions (subtopic 5). The social support topic *sharing status* was found in the following subtopics: sharing current status (subtopic 1), sharing previous experience (subtopic 2),

and sharing status relatives (subtopic 8). Based on the visualization of the topics (see Figure 1) these subtopics are in the proximity of the affective subtopic, indicating a close semantic resemblance (i.e., subtopics contain similar top words). Here, users proactively posted status updates about their current status and reactively posted their previous status or on the status of relatives. Because the subtopics are better grouped under the social support topic named *sharing status* than under the name *emotional support*, the label was changed to *sharing status* (see Table 3).

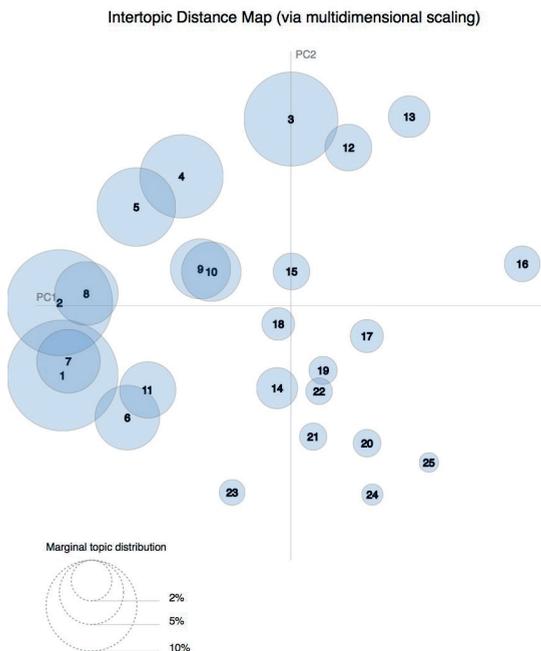


Figure 1. Visualization of Topic Modeling^a

Sub-topic names and proportions: 1, Sharing current status, 14.90%; 2, Sharing previous experience, 13.60%; 3, Cancer treatment information, 10.70%; 4, Emotions and cancer, 8.40%; 5, Member interaction, 7.40%; 6, Side-effects treatment, 5.00%; 7, Affective support, 4.90%; 8, Sharing status relatives, 4.90%; 9, Cancer tests, 4.40%; 10, Rehabilitation, 4.30%; 11, Impact cancer (relatives), 3.80%; 12, After care, 2.60%; 13, Cancer organizations, 2.10%; 14, Cancer detection, 2.00%; 15, Insurance/financial, 1.60%; 16, Cancer research, 1.50%; 17, Nutrition, 1.30%; 18, Employment, 1.30%; 19, Other (alternative) treatments, 1.00%; 20, Medical trials, 0.90%; 21, Gastrointestinal treatment, 0.90%; 22, Hereditary, 0.80%; 23, Treatment consequences, 0.80%; 24, Information sources, 0.50%; 25, External organizations, 0.50 %.

Table 2.
Overview of Sub-topics

Subtopic number	Sub-topic name	Topwords	Sub-topic description	Example post
1	Sharing current status	Hi, cure, chemo, first, day, feeling, head	Patients share their recent experience mostly about treatment.	Hi everyone, today I had the first day of my chemo cure . I'm feeling pretty well, only a little dizzy in my head . (Blog)
2	Sharing previous experience	Months, years, ago, type of cancer, chemo, since, surgery, after	Patients share their previous experiences with cancer.	I also had *type of cancer* and since/after I received chemo/surgery two months/years ago I try to get back to living. (Forum response)
3	Cancer treatment information	Type of cancer, treatment(s), doctor, tumor, examination, complaint, talk	Information about the treatment of cancer.	*Type of cancer* : common complaints include tiredness, loss of appetite and weight loss. If you experience any of these complaints talk to your doctors for an examination . (Library post)
4	Emotions and cancer	Life, emotions, fear, feeling, children, partner, difficult, talk.	The emotional struggle with cancer is discussed in relation to relatives.	Emotions and Cancer: it is common to experience feelings of fear when diagnosed with cancer. How difficult it might be, try talking to your children and partner about it. (Library post)
5	Member interaction	Name, greetings, hi, dear, reaction, thanks, reply, story, experience	Interaction between members and the exchange of experiences.	Hi/Greetings dear *Name* , thank you/thanks for your reply/story/experience . (Forum response)
6	Side-effects treatment	Pain, bother, cure, skin, side effects, complain, fluid, blood	Information about side-effects of treatment.	Side effects: complaints often include, pain, blood loss, excess bodily fluids, irritated skin . Patients are also bothered with [...]. (Library post)
7	Affective support	Good, name, best of luck, hi, hope, greetings, think, luck, wish	Messages wishing someone good luck, showing affection and thinking about them.	Hi *name* , Good luck / best of luck . I hope everything works out. I think of you. Greetings, *name* . (Blog response)

Subtopic number	Sub-topic name	Topwords	Sub-topic description	Example post
8	Sharing cancer status relatives	Hospital, father, mother, type of cancer, scan, appointment, doctor, conversation	Sharing status of cancer experience of relatives.	Today I went with my mother/father with *type of cancer* to the hospital for a scan / an appointment with a doctor . (Blog)
9	Cancer tests	Examination, surgery, MRI, tissue, scan, metastasis, home, physician, surgeon	Tests and treatment methods of cancer.	After an MRI/ Tissue scan / Scan for metastasis , you can go home to wait for the results. (Library post)
10	Rehabilitation	Bother, fatigue, recovery, complaints, condition, exercise, sport, rehabilitation	Information on how to deal with tiredness and how to obtain a better condition / way of living.	Rehabilitation : patients are often bothered with various complaints concerning fatigue : the best way to recover is to slowly increase your condition by exercise/sport . (Library post)
11	Impact cancer on relatives	Wig, bald, deceased, somber, children, sister, grandmother, father	The impact of cancer (by close relatives) on oneself/others.	My grandmother/sister/child/father is feeling very somber about being bald due to chemo and having to wear a wig . (Blog post)
12	After care	Kankernl, group, discussion group, foundation, walk-in clinic, contact, website, organization	Information about the after care, and sources that provide after care.	More information can be found on the website of kanker.nl . Here you will find information about discussion groups, walk-in clinics , and contact information. (Library post)
13	Cancer organisations	Type of cancer, information, Dutch Cancer Society [kwf], Dutch Federation of Cancer Patients' Organizations [nfk], kankernl, website, colofon, patient association, livingwithcancer	Organizations and sources of information about cancer.	For more information on *type of cancer* the following websites of organizations can be contacted: Dutch Cancer Society [kwf] , Dutch Federation of Cancer Patients' Organizations [nfk] ; kanker.nl , [website, colofon], patient association, livingwithcancer [leven met kanker] (Library post)

Subtopic number	Sub-topic name	Topwords	Sub-topic description	Example post
14	Cancer detection	Scan, arm, lymphedema, cea, contrast fluid, pet, blood, microscope, value, substance	Ways in which cancer will be tested.	Pet scan, blood inspection under a microscope , a test of your cea value , or contrast fluids are common ways to test for cancer. (Arm) lymphedema is an often-mentioned side effect of treatment. (library post)
15	Insurance/financial	Reimbursed, (life)insurance, money, payment, own, cost, euro, experiential, practical support	Information about insurance and coverage of different treatments and facilitating services.	Insurance will reimburse most (non-experimental) treatment However, some costs for example for practical support (up to xxx euro) need to be paid for by yourself. (Library post)
16	Cancer research	Article, study, research, scientific, sexuality, Curcuma, test, clinical, effect	Information about cancer research and related topics.	A new research article/ scientific study of a clinical test of the effects of Curcuma on [...]. (Library post)
17	Nutrition	Nutrition, food, sugar, fruit, meat, drink, tea, fish, fat, diet	Information about how to deal with diet and nutrition both during and after treatment.	Nutrition : a good diet could help recovery, some foods and drinks could help: try to eat fruit and fish/meat . Drink lots of tea and avoid too much sugar . (Library post)
18	Employment	Work(ing), employer, Employee Insurance Agency [UWV], sick, insurance, company doctor, colleague, supervisor, contract	Information about employment, laws, and organizations concerned with work and disease.	How to deal with working during cancer? If you have or had a contract your employer possibly has insurance for sick leave. Talk to your employer and company doctor to discuss the options. In general, you are covered by the Employee Insurance Agency and you should contact them too. (Library post)
19	Other (alternative) treatments	Cannabis, weed oil, usage, oxygen therapy, cold cap	Information about treatments to limit the side effects or to address cancer itself.	To deal with side effects some patients report positive experiences with the use of a cold cap after radiation, oxygen therapy or the use of cannabis/weed oil . (Library post)

Subtopic number	Sub-topic name	Topwords	Sub-topic description	Example post
20	Medical trials	Trial, reimbursement, guinea pig, gene, database, patient card	Information about medical trials and costs.	A medical trial database exists in which for example gene therapy and reimbursement is discussed. (Library post)
21	Gastrointestinal treatment	Stoma, surgery, bowel, colon, gist, stool, oxaliplatin, hipec	Colorectal cancer specific information.	For colorectal cancer or gist surgery and oxaliplatin-based hipec in combination with a stoma are treatment options. (Library post)
22	Hereditary	Mutation, hereditary, condition, genetic testing, pregnancy	Information about the hereditary of cancer including tests and pregnancy.	Questions about the genetic and hereditary side of cancer often come to mind during pregnancy . Genetic testing could help reduce stress and shed light on mutations . (Library post)
23	Treatment consequences	Bladder, Incontinence, neuropathic, lipofilling, retained, spasm, catheter, prostate, prothesis	Information about living with the consequence of treatment.	After treatment, especially when the prostate is involved, bladder problems and incontinence are a problem. (Library post)
24	Information sources	Library, rehabilitation program, to inform, look, placed, movie	Discussion of information recourses.	More information can be found by taking a look in the library of this website, following a rehabilitation program or watching this movie to inform you about this topic. (Library post)
25	External organizations	Care, cooperation, Davinci, Dutch Cancer Society [kwf], organization, cancer research, alpe d'HuZes	Organizations that are focused on research, development, or appliance of cancer medication or raising money to do so.	Many organizations and events are held to support cancer patients and cancer research . For example, the Dutch Cancer Society is a large organization that provides patients with information and care . A sporting event like Alpe d'HuZes gathers funds to support cancer research . (Library post)

Table 3.
Mean Topic Scores Comparison per Platform

Social support category	Social support topic	#	Subtopic	Blog ^a	Forum ^b	Library ^c	Questions ^d
Informational support	Cancer specific information	9	Cancer tests	2.38 ^{bed}	1.67 ^{ac}	13.95 ^{abd}	1.83 ^{ae}
		14	Cancer detection	1.26 ^{bed}	0.57 ^{ac}	7.73 ^{abd}	0.44 ^{ae}
		3	Cancer-treatment information	2.58 ^{bed}	4.56 ^{ac}	50.53 ^{abd}	4.32 ^{ae}
	Treatment related information	6	Side-effects treatment	3.51 ^{bed}	2.45 ^{ac}	9.73 ^{abd}	2.46 ^{bc}
		19	Other (alternative) treatments	0.53 ^{bc}	0.68 ^{acd}	1.97 ^{abd}	0.49 ^{bc}
		21	Colorectal cancer	0.48 ^c	0.43 ^c	2.50 ^{abd}	0.41 ^c
	Rehabilitation information	23	Treatment consequences	0.61 ^{bc**d}	0.47 ^{ac}	0.74 ^{**bd}	0.46 ^{ae}
		10	Rehabilitation	2.11 ^{cd}	2.09 ^{cd**}	14.60 ^{abd}	1.55 ^{ab**c}
		12	After care	1.33 ^{bed}	1.77 ^{acd}	8.66 ^{abd}	0.73 ^{abc}
	Surveillance and health information	17	Nutrition	0.90 ^{cd}	0.70 ^c	2.85 ^{abd}	0.54 ^{ae}
		22	Hereditary	0.65 ^{bed}	0.41 ^{acd}	1.84 ^{abd}	0.29 ^{abc}
		11	Impact cancer (on relatives)	4.98 ^{bed}	1.22 ^{ad*}	0.95 ^e	0.72 ^{ab*}
	Interpersonal/social information	4	Emotions and cancer	6.80 ^{bed}	4.32 ^{acd}	18.08 ^{abd}	2.11 ^{abc}
		15	Insurance/financial	1.40 ^{bed}	0.97 ^{acd}	1.84 ^{abd}	0.50 ^{abc}
		18	Employment	1.00 ^{bed}	0.74 ^{acd}	2.43 ^{abd}	0.40 ^{abc}
	Financial / legal information	13	Cancer organisations	0.60 ^{bc}	0.95 ^{acd}	10.42 ^{abd}	0.57 ^{bc}
		16	Cancer research	0.97 ^{cd}	1.14 ^{cd**}	3.33 ^{abd}	0.56 ^{ab**c}
		20	Medical trails	0.78 ^{bed}	0.44 ^{acd**}	1.55 ^{abd}	0.31 ^{ab**c}
	Medical system information	24	Information sources	0.40 ^{bed}	0.29 ^{ac}	0.97 ^{abd}	0.23 ^{ac}
		25	External organisations	0.36 ^{bed}	0.21 ^{acd*}	0.90 ^{abd}	0.16 ^{ab*c}
		7	Affective support	4.97 ^{bed}	2.70 ^{acd**}	0.34 ^{abd}	2.40 ^{ab**c}
	Referral other information sources	5	Member interaction	5.28 ^{bed}	6.07 ^{acd}	1.12 ^{abd}	5.58 ^{abc}
		1	Support from others and groups	19.55 ^{bed**}	5.05 ^{acd}	1.40 ^{ab}	3.05 ^{ab}
2		Sharing current status	10.20 ^{cd}	10.51 ^{cd}	2.79 ^{abd}	9.48 ^{abc}	
Esteem support	8	Sharing previous status	4.85 ^{bed}	2.64 ^{ad}	2.52 ^a	2.02 ^{ab}	
	Network support	8	Sharing status relatives	4.85 ^{bed}	2.64 ^{ad}	2.52 ^a	2.02 ^{ab}
		8	Sharing status relatives	4.85 ^{bed}	2.64 ^{ad}	2.52 ^a	2.02 ^{ab}
Emotional support	8	Sharing status relatives	4.85 ^{bed}	2.64 ^{ad}	2.52 ^a	2.02 ^{ab}	
	8	Sharing status relatives	4.85 ^{bed}	2.64 ^{ad}	2.52 ^a	2.02 ^{ab}	

^a all letters, unless otherwise specified (i.e., *), indicate $p < 0.001$. ^{*} $p < .05$. ^{**} $p < .01$ example ; ^{bed} indicates the mean score for that topic differ significantly from the mean score for that topic on forum, library, and question with $p < 0.001$.

Different Platforms for Different Needs

We explored how peer- and expert-generated cancer-related platforms differ from each other in terms of the social support provided. Overall, the MANOVA shows significant differences between the platforms of all 25 subtopics (see Table 3 for the complete table). While the social support topics were not strictly divided between the platforms, the platforms differed in the degree to which social support topics were present in the different platforms.

Informational support. Informational subtopics were found most in the library platform of the website (9, 14, 3, 6, 19, 21, 23, 10, 12, 17, 22, 4, 15, 18, 13, 16, 20, 24, and 25). To illustrate, within the topic *cancer specific information*, the subtopic cancer tests (subtopic 9) is covered more in the library than it is in all other platforms, including expert questions ($M_{\text{library}} = 13.95$, $M_{\text{blog}} = 2.38^{*1}$, $M_{\text{forum}} = 1.67^{*}$, and $M_{\text{Questions}} = 1.83^{*}$, see Table 3). Within the topic *treatment-related information*, the subtopic cancer treatment information is most dominant, i.e., this subtopic was covered more often in the library than in all other platforms (see subtopic 3 in Table 3). The same holds true for the following topics within informational support: *rehabilitation information* (rehabilitation; subtopic 10), *surveillance and health information* (nutrition; subtopic 17), *financial and legal information* (employment; subtopic 18), *medical system information* (cancer organizations; subtopic 13), and *referral to other sources* (information sources; subtopic 24). The topic *interpersonallsocial information* showed mixed findings. While emotions and cancer (subtopic 4) were covered more within the library than they were in all other platforms, impact cancer (relatives) (subtopic 11) was covered more on blogs than it was in all other platforms. In sum, the library showed the highest coverage in topics concerning general cancer-related information regarding the cancer patients' whole journey, from diagnosis through after care.

Esteem, network, and emotional support. Within the social support topic *coping and spiritual*, the subtopic affective support (subtopic 7) is prominent. This topic was covered more on blogs than it was on all other platforms ($M_{\text{blog}} = 4.97$, $M_{\text{forum}} = 2.70^{*}$, $M_{\text{library}} = 0.34^{*}$, and $M_{\text{Questions}} = 2.40^{*}$). Within the topic *support from others and groups*, member interaction (subtopic 5) was found, which was covered more on forums than it was on all other platforms. For *sharing status*, a nuanced image appears: sharing current status (subtopic 1) and sharing status relatives (subtopic 8) were covered more on blogs than they were on discussion forums and other platforms ($M_{\text{blog_subtopic1}} = 19.28$, $M_{\text{forum_subtopic1}} = 5.05^{*}$, $M_{\text{library_subtopic1}} = 1.40^{*}$, $M_{\text{Questions_subtopic1}} = 3.05^{**2}$; $M_{\text{blog_subtopic8}} = 4.85$, $M_{\text{forum_subtopic8}} = 2.64^{*}$, $M_{\text{library_subtopic8}} = 2.52^{*}$, and $M_{\text{Questions_subtopic8}} = 2.02^{*}$). Sharing previous experience,

1 * = $p < 0.001$

2 $p < 0.05$

however, was found equally on blogs and discussion forums, where it was found more often than it was on the library and question-and-answers platforms.

Discussion

This study investigated the different social support needs and topics on online health information platforms. A theoretical model integrating social support needs and topics was developed (i.e., the model of patients' social support needs) and applied to different online platforms using computer-assisted content analysis. Results showed differences between expert and peer-generated platforms and differences within these types of platforms. Expert-generated platforms generally included informational support and related social support topics focusing on cognitive needs, whereas peer-generated platforms generally included affective support and related social support topics focusing on affective needs. When looking at the differences within one types of platform we found that users talk differently about their experiences on different peer-generated platforms (blogs and forums). These results demonstrate that the platforms fundamentally differ in terms of content. As these platforms may influence the fulfillment of social support needs we can expect that these platforms also affect patient outcomes differently. Future research should therefore explicitly distinguish which platforms are being studied.

On a methodological level, the current study showed the benefits of using a hybrid method, in which a computational social science method is combined with a theoretical a priori–defined model. It allowed us to use a theoretical model to aid interpretation of the results but at the same time to remain open for unexpected findings. For example, many of the subtopics identified were similar to the social support topics that were part of the theoretical model. However, the results indicated that the original model should be extended with the additional social support topic named *sharing status*. To provide informational support, users shared (previous) status updates about themselves or relatives with other users. Although not included in previous typologies of patient needs, previous research highlighted the patient's need to provide their knowledge, quote their experiences, and share their progress online (Eysenbach et al., 2004; Gooden & Winefield, 2007; Coulson, 2005; Wang et al., 2015). If a supervised machine learning approach was used instead of an unsupervised machine learning approach this topic would have remained missing in the proposed model. In sum, the current approach allowed for additional topics to emerge from the data.

While most of the social support topics as identified in the theoretical model were found, three topics were not identified (i.e., *prognosis information*, *body image*, and *tangible assistance*). This finding does not necessarily mean that these topics were not covered in the

online context per se. We chose to conduct our analysis with 25 topics. While 25 topics made interpretation of the topics possible, this number might not have been sufficiently discriminative to differentiate between very specific topics. Another explanation can be found in the definition used. For example, the definition used to identify tangible assistance was maybe difficult to find online (Coulson et al., 2007). Words in this definition such as “concrete” and “physical action” were previously mentioned concerning offline tangible assistance (Coulson et al., 2007). Future research should redefine the definition appropriate to the online context. The definition should cover examples such as “I’ll email you details of this diet ... I hope it helps!” or “I am happy to help any way I can ... just let me know” (Coulson, 2005, p.583). While most of these examples do not provide tangible evidence of support, the willingness to help is evident in this definition.

To further specify and expand the proposed model, the current study should be replicated using different analyses and perspectives. As an illustration, our model can be used as a starting point for future research for supervised machine learning on different online platforms. By applying this method, a more nuanced picture and more specific topics can be identified. For example, using annotated data on how certain topics are discussed would offer a deeper understanding of the nature of patients’ needs. While the current study included multiple, highly-used platforms, these platforms were all part of one source, a Dutch website, that focused on one illness, i.e., cancer. Therefore, generalizability to other countries, platforms, illnesses, and cultures is unknown. For instance, popular social media platforms such as *Facebook*, *Twitter*, and *YouTube* contain “countless discussions of health, illness, and medicine” (Lupton, 2016, p.55). These platforms offer different experiences to the user (e.g., more direct contact, closer-knit groups, and videos) and receive scarce scholarly attention. Analyzing these platforms using the current theoretical model could replicate and validate our findings as well as further improve our understanding of online health information platforms. The model can be further expanded by including more types of diseases across more countries and cultures. Especially when the diseases are considered taboo. In this latter case, online health information might be even more important to these patients. Similar differences in reliance on different sources of health information could be found in other countries and cultures in which medical experts’ expertise is more highly valued. Possibly this limits the dependence on online health information. Future research in other countries showing a higher difference in power between individuals (e.g., China, Japan, and Brazil; Hofstede, 2011), and thus more reliance on experts for information could broaden our understanding of the role online health information in the context of other sources.

Last, researchers are encouraged to consider group interaction on blogs and discussion forums. Due to the current individual focus in our model, the kinds of needs fulfilled by the online interaction between users remain unclear. Given the large degree to which

these responses are given, clearly, some needs are fulfilled. Furthermore, due to the nature of the analysis applied, only the needs and content of posters are analyzed. However, previous research showed most users do not actively write on these platforms but merely read them (i.e., lurkers; Coulson, 2005). Future research should therefore apply different techniques (e.g., pop-up online surveys or focus groups) to identify the needs and motives of this group of users.

Technological advances are changing the way patients search for information, manage their health and the patient-provider relationship (Asan & Carayon, 2017). Technological and health care advances provide the means to more effectively and less expansively manage chronic diseases (Stephanidis et al., 2019). With these technological advances and the availability of online health information platforms, more content (i.e., data) is created (Shah et al., 2015; Topol, 2015; Sillence et al., 2006). How this data is gathered, shared and, used can further improve our understanding of how different stakeholders use this information to manage health (Victorelli, Dos Reis, Hornung, & Prado, 2019; Branford, 2019). As a result of this ever-increasing amount of data, the need to better order and search content online becomes a priority. Insights originating from the current study could influence practice in this regard. Two main suggestions that will help aid and improve content ordering, patients' health information seeking behavior, and in turn, patient-provider interaction will be discussed.

On the one hand, design factors in the interface could help users to navigate and match content to their needs. The model of patients' social support needs can be used as a blueprint for ordering online content. By ordering the content by the proposed model, the content will follow the same route from very "abstract" social support needs towards increasingly precise needs and topics (Wilson et al. 2002). Second, using the algorithms to annotate the data based on patients' social support needs, the content can automatically be accompanied by visuals that indicate to the users which topic is discussed. For example, platforms can include visual cues such as an icon of a brain for cognitive content or an icon of a heart for affective content. Alternatively, parts of texts that match the social support needs of the user can be highlighted or include an exclamation mark that would signal patients to the relevancy of those parts based on their indicated social support needs. This enables patients to intuitively browse and more easily find content based on their needs. A well-designed website, with a focus on information seeking (ordering) and integration (visual cues), could benefit patients by limiting the possibility of encountering misinformation and/or reducing cognitive overload (Lyu & Li, 2019; Blandford Furniss, & Vincent, 2014).

On the other hand, our results can help providers, patients, and relatives to find content more easily and in turn, positively influence patient-provider interaction and patient

outcomes. The algorithms used in our analysis can be used to optimize searches from a keyword-based approach to a semantic-similarity-based approach in which the context of keywords are taken into account. The word clusters identified during our analysis included words that are linked together through their latent meaning and thus provide context to each other. These can be used to help users find the right content. Search approaches like semantic-similarity, are found to provide better search results on platforms such as forums (Franco-Salvador, Kar, Solorio, & Rosso, 2018). The context of the words will help with overcoming problems due to polysemy (i.e., words with multiple meanings depending on the context) and synonymy words (Malve & Chawan, 2015). For example, using a semantic-similarity-based approach instead of a keyword-based approach, a patient searching with a search query like “weed oil” or “alternative treatment” will not only see content that include that specific keyword, but also parts that contain synonyms or related complementary treatments (e.g., tbc oil, complementary treatment, or acupuncture). These words are part of the same word cluster and thus might fulfill the need of a user searching for alternative treatments. This will make a patients’ search strategy more intuitive and complete. In the future, we could formalize these semantics into ontologies of which the proposed model could be a starting point. This ontology would even allow for searching across multiple sources of information (Malve & Chawan, 2015).

In sum, these two applications have the potential to make online content more accessible, easier to navigate, and tailored towards patients’ needs. In a health care setting where patients’ empowerment is important but the patients also deal with emotional and cognitive uncertainty due to their health condition, easy access to health information is an important topic (Huang & Haried, 2019). A more intuitive and better functioning search engine will make it easier to find more relevant and complete information particularly for older patients and those with low health or technology literacy (Blandford, 2019; Topol, 2015; Becker, 2004). Research shows that patients who are more confident about their search results are more likely to engage in talking about that information with their medical expert (Diaz, Sciamanna, Evangelou, Stamp, & Ferguson, 2005; Sommerhalder, Abraham, Zufferey, Barth, & Abel, 2009). These discussions in turn allow for an appraisal of the online information, resolving misunderstandings, a higher degree of shared decision making, and better patient outcomes (Benetoli, Chen, & Aslani, 2018; Sanders & Linn, 2018; Asan & Carayon, 2017).

3

CHAPTER 3

Patients' Convergence of Mass and Interpersonal Communication on an Online Forum: Hybrid Methods Analysis

This chapter is an adapted version of the published article:

Sanders, R., Araujo, T. B., Vliegenthart, R., van Eenbergen, M. C., van Weert, J. C., & Linn, A. J. (2020). Patients' Convergence of Mass and Interpersonal Communication on an Online Forum: Hybrid Methods Analysis. *Journal of Medical Internet Research*, 22(10), e18303. doi:10.2196/18303

Abstract

Introduction: Patients are increasingly taking an active role in their health. In doing so, they combine both mass and interpersonal media to gratify their cognitive and affective needs (i.e., convergence). Owing to methodological challenges when studying convergence, a detailed view of how patients are using different types of media for needs fulfillment is lacking.

Objective: The aim of this study was to obtain insight into the frequency of reported convergence, how convergence affects what posters write online, motives for posting, and the social support needs posters are trying to fulfill.

Method: Using a hybrid method of content analysis and supervised machine learning, this study used naturally available data to fill this research gap. We analyzed opening posts ($N = 1708$) of an online forum targeting cancer patients and their relatives (*Kanker.nl*).

Results: Nearly one-third of the forum opening posts contained signs of convergence in mass or interpersonal media. Posts containing mass media references disclosed less personal information and were more geared toward community enhancement and sharing experiences compared to posts without convergence. Furthermore, compared to posts without signs of convergence, posts that included interpersonal media references disclosed more personal information, and posters were more likely to ask for the experiences of fellow users to fulfill their social support needs. Within posts containing signs of convergence, posts including interpersonal media references reported fewer shortages of information, disclosed more information about the disease, and were more active in seeking other posters' experiences compared to posts containing mass media references.

Conclusions: The current study highlights the intertwining of media platforms for patients. The insights of this study can be used to adapt the health care system toward a new type of health information-seeking behavior in which one medium is not trusted to fulfill all social support needs. Instead, providers should incorporate the intertwining of sources by providing patients with reliable websites and forums through which they can fulfill their social support needs.

Introduction

Patients have the need to know and understand (i.e., cognitive needs) and the need to feel acknowledged and understood (i.e., affective needs; Bensing & Verhaak, 2004). Currently, patients take an active role in the management of their health and in doing so, they combine mass and interpersonal communication to gratify their cognitive and affective needs (hereafter known as *social support needs*; Blandford, 2019). By using mass and interpersonal communication, patients engage in a process that is called *convergence* (Kreps, 2017; Vorugunati, Grunfeld, Makuwaza, & Bender, 2017; Walther & Valkenburg, 2017). According to Kreps (2017) convergence can be defined as “the sequence of impersonal to interpersonal interactions” (p. 519, type 1 convergence) or the “conduct of interpersonal and peer discussions about health-related issues in virtual discussion spaces of various kinds” (p. 521, Kreps, 2017; type 2 convergence). We adapted and broadened this definition to include convergence between and within mass or interpersonal communication to apply to the current study. We consider convergence as a process in which either one mass communication source and one interpersonal communication source (intermedium convergence), or two mass communication sources (intramedium convergence), are being used to fulfill the user’s social support needs. For example, patients learn about their disease through a consultation with a medical expert (interpersonal communication) and then validate the advice of the medical expert by visiting a website (mass communication; intermedium convergence; van der Meij et al., 2018; van Eenbergen, van de Poll-Franse, Heine, & Mols, 2017; Lobchuk, McClement, Rigney, Copeland, & Bayrampour, 2015). An example of intramedium convergence is the use of treatment experience from a fellow patient’s blog post in one’s own blog post.

These examples show how patients use mass and interpersonal communication to fulfill their social support needs. However, research into this topic often focuses on one singled-out communication source. As a consequence, research does not provide insights into how communication sources affect each other and how social support needs differ depending on the sources used. Answering these questions is important since patients have different communication sources at their disposal. Especially when it comes to online health information, patients often struggle to understand the complex information online, have difficulties to assess whether the information is reliable, and might feel overwhelmed or experience information overload (Seale, Ziebland, & Charteris-Black, 2006; Eysenbach, Powell, Kuss & Sa, 2002). Therefore, patients and medical experts should work together in providing, validating, and discussing information. To determine which (online) source fits best, insights are needed on how patients combine sources, and how the combination of sources affects social support needs. Ultimately, part of the costly and limited time of the medical expert could be used for referring to sources that can reliably fulfill part of the patients’ social support needs.

One explanation for the research gap on how patients combine multiple sources to fulfill their social support needs can be found in the methodological challenges faced when studying this process. The scarce research in health communication in which both mass and interpersonal communication are taken into account tends to rely on more traditional research methods, such as surveys (Batenburg & Das, 2014; Nwosu & Cox, 2000), interviews (Caiata-Zufferey, Abraham, Sommerhalder, & Schulz, 2010), and focus groups (Rupert et al., 2016). These methods can be affected by selection bias, recall bias, and social desirability (Batenburg & Das, 2014). By using a hybrid method consisting of content analysis and supervised machine learning (SML), we will be able to surmount the limitations of these traditional methods (Shah, Cappella, & Neuman, 2015). The hybrid method combines a content analysis of real-life communication and SML. We use natural unsolicited data, i.e., data that are not written as part of research but have been written by the user at the time their social support needs arose. The benefit of this method is that large amounts of already existing natural data can be used to study the current topic.

A good starting point is the analysis of data from online health forums targeted towards patients. Forums provide a natural database of people's online activities. In forum opening posts, posters often provide information about their situation at the time of writing, which often includes previously-used communication (i.e., signs of convergence), the outcome of this communication effort (i.e., motives to start the forum post), and the social support needs they are trying to fulfill. Additionally, background information about the poster is often included (e.g., stage and type of the disease and whether the poster him/herself or a family member is diagnosed with the disease; Kreps, 2017; Abdul-Muhsin, Tyson, Raghu, & Humphreys, 2015). Thus, by using this hybrid method we are able to gain more insight into how often patients combine mass and interpersonal communication, the reason as to why they engage in convergence, which need they try to fulfill, and whether the content of forum posts differ based on the communication sources they used prior to writing the post. The following research aim is central in this study: *What signs of convergence can be detected in forum opening posts, how frequent does convergence occur, what kind of social support needs are patients trying to fulfill by engaging in convergence, and how do forum post characteristics (i.e., motives, information about the poster, and social support needs) differ for different kinds of convergence?*

The current study uses forums in the context of cancer. Cancer patients are confronted with many questions and uncertainties during their sickness (Leydon et al., 2000; Sanson-Fisher et al., 2000). Furthermore, online platforms such as forums and interpersonal communication with a health care provider are the two most important sources of information for cancer patients (Hong, Peña-Purcell, & Ory, 2012).

Theoretical Background

Interpersonal Communication

In general, most patients consider medical experts to be the most trusted source of information (Shea-Budgell, Kostaras, Myhill, & Hagen, 2014). In a review by Shea-Budgell and colleagues (2014), patients place a high level of trust in medical experts due to their expertise on topics that patients find most important, including treatment, screening, testing, and detection. Furthermore, their medical and informational training and, to a lesser degree, the emotional support they provide during a consultation are mentioned as factors that instill confidence (Hesse et al., 2015; Prestin, Vieux, & Chou, 2015; Xiao, Sharman, Rao, & Upadhyaya, 2014). Nevertheless, between 40% and 90% of patients report unmet social support needs after their consultation with a medical expert (Puts, Papoutsis, Springall, & Tourangeau, 2012; Iconomou, Vagenakis, & Kalofonos, 2001). Multiple reasons can be given for these unmet social support needs; patient-related reasons include unmentioned concerns, a lack of trust in a particular medical expert, and information overload (Brandes, van der Goot, Smit, van Weert, & Linn, 2017). Examples of medical expert-related concerns are time constraints and a lack of experience (Hack, Degner, & Parker, 2005). Therefore, patients also rely on other sources for needs fulfillment, such as online forums. Patients expect their medical experts to discuss the content they found via other sources and to offer their professional take on it (Sommerhalder et al., 2009). By discussing online health information with their provider, patients engage in intramedium convergence.

Online Forums

Online forums are often used by patients and their relatives and can be considered as virtual communities. Virtual communities exist in many different areas, cover many topics, and connect groups with a variety of shared characteristics. In this study, we adopt the definition of Rheingold (2000), who states that virtual communities are: “[...] social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace” (p. 5). Many patients encounter various social support needs and use multiple communication sources to fulfill these social support needs. As a result, these patients are active in online forums while also often having contact with other sources, such as medical experts (Gooden, & Winfield, 2007). Patients use these platforms to gain understanding about their disease but also to connect and exchange experiences and support with others in comparable situations (Lobchuk et al., 2015; Sanders et al., 2020a; van Eenbergen et al., 2017). By encouraging and enabling active participation (e.g., by opening a thread on a topic that is personally relevant), forums have the potential to provide different types of support to the user, such as to receive the support of their peers, to feel empowered through information provision, and to recognize themselves in

stories from peers and thereby feel less isolated (Sinha, Poter, & Wilson, 2018; Batenburg & Das, 2014). The malleability of forums in addressing patients' social support needs and the ability to do this at any time might be a key reason why patients turn to these forums.

Convergence and Underlying Motives

Many patients decide to combine multiple sources to fulfill their social support needs. Generally, 25% to 83% of patients search for online health information before or after a consultation with their medical expert (Bender et al., 2019; van Eenbergen et al., 2019; Linn et al., 2019; Sanders & Linn, 2018; Bylund, 2011). Patients seem to use online health information in addition to a consultation to prepare themselves (Linn et al., 2019; Caiata-Zufferey et al., 2010), to complement the information given by the medical expert (Puts et al., 2012; Caiata-Zufferey, et al., 2010; Iconomou et al., 2001), as well as to validate and/or challenge the information given by the medical expert (Linn et al., 2019; Caiata-Zufferey et al., 2010).

To understand why patients use multiple sources, the optimal matching model can be used (Cutrona, 1990). This model states that to fulfill patients' social support needs, these social support needs should be matched with the right type of support. For example, if the patient feels the need to prepare for a consultation or wants to complement, validate, or challenge the information that is given by the medical expert, this need can be fulfilled by gathering factual information from other sources. On the other hand, if the patient feels lost and alone, this need might not be fulfilled by receiving information about the upcoming treatment but by receiving emotional support that helps with the emotional aspects of being sick. According to the optimal matching model, patients actively choose the communication channel which they believe has the highest potential to fulfill their current social support needs. A patient who feels (s)he should prepare for the consultation is more likely to choose online medical libraries to fulfill these social support needs, but a patient who feels lost will more likely turn to online health forums and blogs, on which interaction with fellow patients is possible (Sanders et. al., 2020a; Chen, Li, Liang, & Tsai, 2018; Kreps, 2017; Stafford, Stafford, & Schkade, 2004; Rubin, 2002). This exploratory research contributes to the optimal matching theory by identifying whether and how patients fulfill their social support needs by using multiple sources at their disposal and how these sources are intertwined.

Research Questions

In sum, we believe that forum posts provide a natural database of peoples' communication activities, and these forum posts allow us to gain a better understanding of the interplay between communication channels. Therefore, RQ1 is proposed as follows: *What is the frequency of signs of convergence in forum opening posts?* Furthermore, these forum posts can provide a natural registration of the motives for using different media (e.g., after seeing

a doctor or reading online health information) to fulfill specific social support needs. Therefore, RQ2 is proposed as follows: *What social support needs are patients trying to fulfill by opening a forum post?* By using a hybrid method to analyze these forums, we are able to also capture other relevant information such as the disclosure of information about the poster and the motive for posting (Kreps, 2017; Abdul-Muhsin et al., 2015). These aspects are important to providing insight into how users in different situations gratify their social support needs and/or the social support needs of relatives by using multiple sources. We, therefore, propose RQ3 as follows: *How do motives (3a), information about the poster (3b), and the social support needs (3c) differ for different types of convergence?*

Methods

This study uses a hybrid method consisting of a classic social science method (i.e., the framework method; Gale, Heath, Cameron, Rashid, & Redwood, 2013) and a newer computational social science method (i.e., SML). The benefit of this approach is twofold. First, this method allows us to combine unique features from both approaches. On the one hand, the framework method starts from a theory-based codebook (i.e., the use of sensitizing concepts) and is then further developed through an iterative process of (open) coding on a subsample of the data. On the other hand, the coded subsample can then be used to label the whole sample with codes and categories using SML, thereby allowing us to move from open-coded data on a subsample to data that is suitable for quantitative analysis based on the complete dataset, this allows researchers to analyze sample sizes that were impossible to code manually. Second, SML allows us, as well as other researchers and practitioners, to (re)use the trained model on a different dataset or for practical applications. The reuse of the algorithms makes cost-efficient longitudinal research into convergence possible since the models can automatically and consciously be applied to new data.

Data

The current study uses data retrieved from cancer patients and relatives on *Kanker.nl*. Cancer is the most common disease, with a yearly incidence rate of 439.2 per 100,000 men and women (18,078,567 in 2018) and a yearly rate of 163.5 per 100,000 people dying from cancer (9,555,027 in 2018; WHO, 2019). Furthermore, cancer patients and their relatives experience multiple visits with a medical expert and face many questions and uncertainties. In the Netherlands, *Kanker.nl* is one of the largest and best-known Dutch websites for cancer-related information within an online community.

Users are required to register and must provide their name and a valid e-mail address. Participants of all platforms within *Kanker.nl* give (standard) consent for using their data

for research when they register. Ethical approval for the current study was provided by the University of Amsterdam.

For the complete dataset, first, all forum entries ($n = 9,573$) were extracted. Second, only the tread opening posts of the threads were selected ($n = 1,708$). The opening posts were chosen because they are most likely to contain a description of the situation and the need the user wants to fulfill. The median number of words for each thread opening was 608.05 (Min = 3, Max = 20,649). The threads were created between April 2013 and November 2016.

Phase 1: Framework Method

Of all the thread openings, a random sample of 306 posts (17.92%) was manually coded by the first author in multiple iterations. First, using two sensitizing concepts derived from the literature (i.e., *information sources* and *motives for searching health information*), 100 posts were open coded on *signs of convergence* (RQ1), *motives for opening a forum thread* (RQ2), *sought after need* (RQ3), and *personal characteristics* (RQ3); in total, 583 different codes were used for the constructs needed to answer RQ2 and RQ3. Second, these open codes were merged into overarching, latent categories. For example, the distinctions between different medical experts, such as general practitioners, oncologists, and nurses, were merged into a *medical expert* category. Third, the codebook and categories were evaluated on completeness during research meetings with the coauthors (AL, RV, JvW). As a result, several categories were merged again, and more specific categories were added. This process resulted in the following categories: *convergence*, *motive for posting*, *information on poster*, and *needs* (see Table 1 for the codebook). Fourth, the updated codebook was evaluated by the first author and a trained coder (MB) who double coded 20% of the sample. The intercoder reliability was good (range Lotus = 0.98–1.00), Lotus and standardized Lotus scores are displayed per category in Table 2. Fifth, all 306 exported thread openings were manually coded by the first author using the codebook. Sixth, the manually-coded posts were transformed by the first author into binary variables to be used in the second phase.

Codebook. Table 1 contains the categories and codes that were coded during the SML phase. These variables were coded as 0 (not present) or 1 (present). In Figure 1, a fictitious example is given of the extracted concepts from the forum opening posts.

Table 1.
Overview of categories and codes analyzed

Category	Codes/ classifiers	Description	Example
Convergence			
	Mass communication	(1) online and (2) offline media. Mass communication was coded as such when communication channels such as Internet sources (i.e., online) and television and newspapers (i.e., offline) were mentioned.	"[...] on a website I read that [...]"; "This article in today's newspaper [...]"
	Interpersonal communication	Interpersonal communication was coded as such when one of the following communication sources were mentioned: 1) medical experts (e.g., general practitioner, nurse, surgeon), 2) fellow patients, 3) family members, or (4) others.	"My doctor told me that [...]"; "According to my mother [...]"
	No media	Posts contained no references to other media.	"I was wondering if any of you knows something about [...]"
Motive for posting			
		For posts containing mass media or an interpersonal media references, the outcome of this communication event was coded as follows:	
	Conflict	Information is received from a medium that is contradictory to information previously acquired from another medium or contradictory to held beliefs. Resolving this discrepancy is a motive to open a forum thread.	"[...] My doctor told me this treatment is not an option for me, but I heard lots of stories that it was successful [...]"
	Shortage of information	Poster indicates that (s)he received little or no information regarding a topic. To fill this information gap, a forum thread is opened.	"[...] There was no time during the consultation to discuss the trajectory of this alternative [...]"
	New question	Poster indicates that as a result of information provided during the mentioned communication effort, (s)he has new (follow up) questions. Answering these questions is a motive for opening a thread.	"[...] the doctor mentioned this medicine can have a lot of side-effects, but is it common to experience them?"
	Sharing information	Poster wants to share the information / content that was received during the previous communication effort on the forum.	"I read this [website] and thought it might be useful for all of you".
Information on poster			
	Disease or treatment information	Specific stages of the disease (e.g., stage one) or treatment (e.g., after surgery) were described in the post.	"[...] I'm diagnosed with stage one breast cancer"; "[...] After surgery I noticed that [...]"

Category	Codes/ classifiers	Description	Example
	Time indication	Diseases or treatments that were mentioned at “disease or treatment information” stage are further specified with a time indicator.	“One year after my surgery, I went back to the hospital [...]”
	Type of cancer	Type of cancer is mentioned by the poster.	“I have been diagnosed with lung cancer”
	Cancer in the surrounding	The poster him/her-self was not diagnosed but someone close to him or her was.	“My husband has been sick for a few years now, I wonder [...]”
Social Support Needs			
	Community building	The post is meant as a conversational starter, including rhetorical questions and a direct call for discussion. All without asking for experiences or advice.	“What is your opinion about the quality of care in the Netherlands?”
	Sharing experiences	The poster is sharing experiences about the treatment or psychosocial aspects surrounding (living with) cancer.	“For me, this kind of treatment worked very well without too many side-effects” or “For me, it worked to limit the number of social activities in a week”.
	Asking experiences	The poster invites other forum members to share their experiences about a certain topic.	“Who has experience with this?”
	Asking for information	The poster asks for more information about a certain topic or asks for referrals to sources where this information can be obtained.	“Who knows where I can find more information about this?”

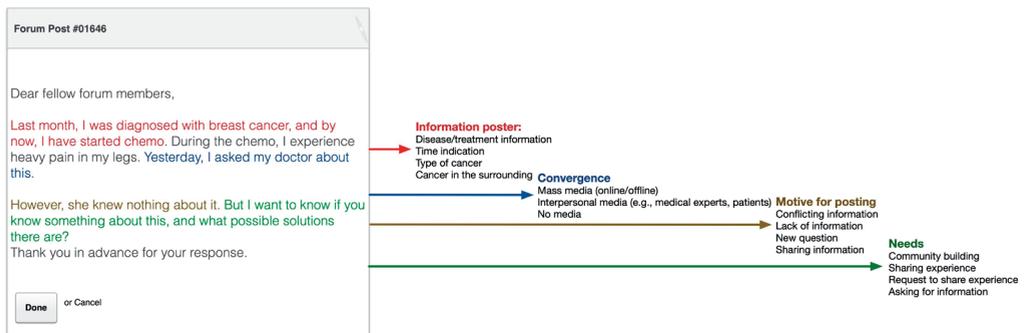


Figure 1. Example of extraction of concepts from forum posts.

Table 2.

Intercoder reliability using Lotus and standardized lotus coefficients per variable.

Concept	Lotus	S-Lotus
Convergence		
Mass communication	1.00	1.00
Interpersonal communication	1.00	1.00
No media	1.00	1.00
Specification convergence		
Online	1.00	1.00
Offline	1.00	1.00
Medical expert	1.00	1.00
Fellow patients	1.00	1.00
Family members	1.00	1.00
Others	1.00	1.00
Motive for posting		
Conflict	1.00	1.00
Shortage of information	1.00	1.00
New question	0.98	0.96
Sharing information	0.98	0.96
Information on poster		
Disease or treatment information	1.00	1.00
Time indication disease or treatment	1.00	1.00
Type of cancer	0.99	0.97
Cancer in the surrounding	1.00	1.00
Social support Needs		
Community building	1.00	1.00
Sharing experience	0.99	0.97
Asking experience	1.00	1.00
Asking information	0.99	0.97

Phase 2: Supervised Machine Learning

We used SML to train classifiers for the references to mass or interpersonal communication (see appendix 1 for a detailed description of the SML phase). A sample of 685 manually-coded opening posts (in two rounds) were used as input for the SML. This sample was split into a training set ($N = 548$) and a test set ($N = 137$) using an 80-20 split. Using *Scikit-Learn* (Pedregosa et al., 2011), the data were preprocessed (see appendix 1 for a detailed overview), and the classifiers were trained using different algorithms, such as support vector classification (SVC), stochastic gradient descent (SDG), multinomial naïve Bayes

(MNB), gradient boosting, and passive aggressive classifier. This was done to evaluate which algorithm would have the best performance for each concept it was trained to predict. In this process, we adopted a gridsearch strategy – testing different combinations of parameters for each algorithm, as well as different options for preprocessing the data.

The quality of the classifiers was assessed based on precision, recall, and F1 scores for their predictions of cases in which the category was present (i.e., for cases in which the reference to mass or interpersonal communication was 1). Precision gives the proportion of the automatically-assigned labels that correspond with the human-labeled data. Recall gives the proportion of the true labels that are found automatically. This often results in a tradeoff between the scores of precision and recall; for example, in cases of a higher recall, the chance that some of the recalled data are false positive grows, and as a result, the precision score goes down. F1 scores are the harmonic mean of the recall and precision. SDG showed to best predict the classifiers *convergence mass media* and *convergence interpersonal media* (recall_{interpersonal} = 0.76, precision_{interpersonal} = 0.96, F1 = 0.85; recall_{massmedia} = 0.86, precision_{massmedia} = 0.92, F1 = 0.89). These classifiers were applied to the complete dataset of opening posts ($N = 1,708$) to create a subsample of opening posts that were likely to contain signs of convergence (45,40%; $N = 771$).

Phase 3: Manual Coding Convergence Posts

To ensure the validity of the automatically-assigned classifiers, the created subsample of posts was checked on correctness. Of the automatically-labeled posts containing signs of convergence ($N = 771$), 245 posts (31,78%) did not contain signs of convergence after manually checking, and were coded as *no media*. Next, the subsample of posts was manually coded by the first author using the codebook for the remaining categories (see Table 1).

Analysis

Before running the analysis, all independent variables were tested on possible issues due to multicollinearity. Only issues concerning *time since diagnosis*, *stage of the disease*, and *type of disease* ($r_{\text{time-stage}} = 0.82$, $r_{\text{time-type}} = .92$) were found, these items were taken together as *disclosure of information about the disease* (eigenvalue = 2.71; $R^2 = .90$; $\lambda = .95$).

RQ1 and RQ2 were answered using descriptive analyses. To compare the outcomes on the dependent variables between posts containing different signs of convergence (RQ3), two multinomial logistic regression analyses were conducted. In these two analyses, the referenced communication channels were the dependent variables (i.e., *no media*, *mass communication*, or *interpersonal communication*). The first regression used *no media* as the reference category and *information on poster*, and *social support needs* as the independent variables. Since the category *motive* was not applicable to the no mass or interpersonal

media category, this category was omitted from this analysis. However, to pinpoint the differences between posts containing signs of convergence, *motive*, *information on poster*, and *social support needs* were included in the second regression analysis, in which *mass communication* was used as the reference category. The outcomes of these analyses are displayed in odds ratios (OR). An R of 1 indicates no differences in probability between the groups compared, whereas a value >1 represents an increased probability, and a value <1 represents a decreased probability (Ranganatha, Aggarwal, & Pramesh, 2015).

Results

Signs of Convergence in Forum Posts

The results show that 30.83% of the complete sample of forum opening posts ($N = 526$) contained signs of convergence. These were divided as follows: $N_{mass} = 324$ (61.60%) and $N_{interpersonal} = 202$ (38.40%). In the following sections, these categories will be described more in-depth.

Of all mass communication references ($N = 324$), 274 (84.57%) referred to online sources (e.g., other members' profiles or blogs, news media articles concerning cancer (patients), and health information websites). Of these, 214 posts (66.05%) contained references to a website. Offline mass communication was referenced 49 times (14.20%), which included references to printed newspapers, books, and television.

Of all interpersonal communication posts ($N = 202$), 162 references (80.20%) were made to medical experts (e.g., oncologists, nurses, and general practitioners), and 14 references (6.93%) were made to family members. These include family members who either had personal experiences with the disease or provided information they received via other sources. Fellow patients who provided information offline were referenced 3 times (1.49%), and 22 references (10.89%) were made to communication events with other people. Often, these events consisted of work-related relationships (e.g., employers, insurers, and rehabilitation agents).

To answer RQ1: almost one-third of all forum openings posts contained signs of convergence and thus included references to either mass or interpersonal communication. When referencing mass communication, mainly online sources were mentioned, whereas for interpersonal communication, medical experts were most often mentioned.

Posters' Social Support Needs

Of all the opening posts, 44.62% of the posts ($N = 344$) represented the need of asking for experiences regarding a specific treatment (e.g., medicine, procedure) or experiences

regarding (dealing with) the (emotional) effects of living with cancer (i.e., dealing with side-effects, reintegration into society, and body image). Next, 34.50% of the forum opening posts ($N = 266$) consisted of community building posts. Here, the poster started a discussion about a particular topic, such as developments in the medical sector, with or without a URL to a news story (online). The third-largest need to open a forum thread was to share one's personal experience. Overall, 18.55% of the posts ($N = 143$) featured this need. Finally, in 9.34% of the opening posts, the poster directly asked for sources to find more factual information on a particular topic, such as (alternative) treatment options.

To answer RQ2: the main need for patients to be fulfilled, as reflected in forum openings post, is that of asking for information related to experiences. This need is followed by that of enhancing the community, sharing one's experiences, and asking for factual information.

Differences in Posts for Different Kinds of Convergence

The first multinomial logistic regression contained the variables from the categories *information on poster* and *social support needs* (adj. $R^2 = .30$) $X^2(12) = -563.27$; $P < .001$ (see Table 3). In posts referencing mass communication, the disclosure of disease-related information was 89% less likely to occur compared to posts that did not include a reference to mass or interpersonal communication (OR = .11, $P < .001$). In contrast, posts including references to interpersonal communication had a 156% higher likelihood of featuring the disclosure of disease-related information (OR = 2.56; $P = .009$) compared to posts containing no references to media. These outcomes mean that the chance of disclosing disease-related information in forum posts in which interpersonal communication are mentioned is higher compared to forum posts with no signs of convergence and lower for posts that include references to mass communication. When looking at the social support needs posters might have for opening a forum thread, differences in social support needs within different types of convergence were found. Higher likelihoods were found for posts including references to mass communication compared to posts containing no signs of convergence for the social support needs: *community building* (OR = 4.73, $P = .002$), *sharing experiences* (OR = 3.91, $P = .003$), and *asking information* (OR = 2.88, $P = .04$). This means that after mass communication exposure, posts have a 373% higher likelihood of containing the need to share the post for community building, a 291% higher likelihood of containing the need to share ones' experience with others, and a 188% higher likelihood of asking for more information compared to no exposure to mass or interpersonal communication. Posts containing references to interpersonal communication had a 268% higher likelihood of displaying the need to ask fellow patients for their experiences (OR = 3.68; $P = .004$) compared to posts containing no signs of convergence.

Table 3.

Differences between posts containing signs of convergence and posts without.

Category	Variable	Regression 1 ^a					
		Mass			Interpersonal		
		OR	<i>p</i>	95% CI	OR	<i>P</i>	95% CI
Information on poster							
	Disclosure of information about the disease	.11	<.001	.06–.20	2.56	.009	1.26 – 5.20
	Cancer in surrounding	1.08	.85	.50 – 2.29	1.51	.10	.92 – 2.49
Social Support Needs							
	Community building	4.73	.002	.92 – 2.49	.21	.06	.04 – 1.10
	Sharing experiences	3.91	.003	1.59 – 9.59	1.71	.21	.75 – 3.89
	Asking for experiences	1.30	.58	.52 – 3.30	3.68	.004	1.50 – 8.99
	Asking for information	2.88	.04	1.04 – 7.98	1.91	.23	.67 – 5.46

^a Reference category = No media

The second multinomial logistic regression contained the variables from the categories *motive*, *information on poster*, and *social support needs* (adj $R^2 = .77$) $X^2(20) = -185.40$; $P < .001$) (see Table 4). Within the category *motive*, in posts referencing interpersonal communication, a shortage of information was 81% less likely to be the reported outcome of the communication effort compared to posts referencing mass communication (OR = .19, $P = .006$). Furthermore, within the category *information on poster*, posts referencing interpersonal communication were 2015% more likely to disclose information about the disease compared to posts referencing mass communication (OR = 21.15, $P = < .001$).

Within the category *social support needs*; posts containing interpersonal communication were 93% less likely to display community building as a need of the post compared to posts referencing mass communication (OR = .07, $P = .004$). Furthermore, posts referencing interpersonal communication had a 227% higher likelihood of asking for other posters' experiences compared to posts referencing mass communication (OR = 3.27, $P = .04$).

To answer RQ3: compared to intramedium convergence, intermedium convergence posts are less likely to be motivated by a shortage of information and more likely to contain information about the posters' condition. Furthermore, again compared to intramedium convergence, intermedium are more likely to display the need for experiences and a less likely the need for community building.

Table 4.
Differences between posts containing signs of convergence

Category	Variable	Regression 2 ^a		
		Interpersonal		
Motive		OR	<i>p</i>	95% CI
	Conflict	2.77	.07	.92 – 8.29
	Shortage of information	.19	.006	.06–.63
	New questions	.83	.69	.30 – 2.23
	Sharing of information	.39	.11	.12 – 1.24
Information on poster				
	Disclosure of information about the disease	21.15	< .001	9.39 – 47.62
	Cancer in surrounding	1.49	.36	.64 – 3.47
Social support needs				
	Community building	.07	.004	.01–.44
	Sharing experiences	.65	.47	.20 – 2.10
	Asking for experience	3.27	.04	1.01 – 10.57
	Asking for information	.77	.70	.20 – 2.90

^a Reference category = Mass communication

Discussion

This study gained more insight into (the occurrence of) convergence using natural unsolicited data. Overall, intramedium and intermedium convergence resulted in posts containing different content and aiming to fulfill different social support needs. We found that nearly one-third of all forum opening posts in our sample contain signs of convergence by referencing either mass or interpersonal communication in the post. For intramedium convergence, online sources such as websites, forums, and online news articles were most often mentioned, often accompanied by a link to that source. In this way, posters seem to fulfill their need to help build the online community and initiate a discussion or to share experiences. Post containing intermedium convergence often included references to a consultation with a medical expert. In these posts, users reported less shortage of information, disclosed more about themselves, and asked more experiences from other users compared to posts containing intramedium convergence.

Our findings further emphasize 1) the frequency of reported convergence and 2) how intertwined these sources are. The main interpersonal communication source that was mentioned in the posts was that of a medical expert. This outcome is in line with previous research in which the medical expert, together with the Internet, is named the most important source of information for patients (Xiao et al., 2014; Hong et al., 2012, Muusses, van Weert, van Dulmen, & Jansen, 2012). We found that one-third of the posts contain signs of convergence. The number of patients who use more than one medium is likely to be higher for two reasons. First, we only looked at specific types of convergence occurring in forum posts; however, based on previous research (e.g., Sanders & Linn, 2018), we know that signs of convergence also occur at the medical encounter and that different types of convergence exist. For example, during medical encounters patients could discuss a forum (s)he have read before the consultation and thus engage in intermedium convergence (online forum – medical expert), or engage in intramedium convergence (i.e., medical expert-medical expert) by referencing a medical expert during the consultation who have conducted a second opinion. Second, we only coded explicit signs of convergences, while previous research also shows that patients implicitly mention different sources (Bylund & Makoul, 2005). Unique to this study is that while previous studies have often examined both sources independently, the current results show how interdependent these sources are and how they are likely to continue to merge in the future. For example, a poster who just went to an appointment with a medical expert may have received lots of information (convergence). After interpersonal communication, there is a lower likelihood that the patient experienced a shortage of information (motive). However, the patient might have missed information about how other patients experienced the situation, which motivates the patient to go online, write about their situation, and ask fellow patients for their experiences (need). According to

the optimal matching theory (Cutrona, 1990), patients actively chose a medium that likely fulfills their social support needs. In the context of support, some patients actively start participating in forums to find what only fellow patients can provide: experiences (Rupert et al., 2016; Lupton, 2013; Eysenbach, Powell, Englesakis, Rizo, & Stern 2004). It also highlights the importance and added value of studying information sources in an interdependent context instead of independently. In light of the increased availability of different information on platforms, the Internet seems to be a promising venue to fulfill social support needs that are not fulfilled during a consultation. Taking the notion of the optimal matching theory further, one could argue that it should not be a problem if patients report unmet social support needs based on their exposure to one medium, as another medium might be better able to fulfill these unmet social support needs. However, the medical expert and patient should work together to make sure credible sources of information are known and available to the patient to fulfill their social support needs.

Based on our results, posters seem to require information provided by other patients combined with the information provided by the medical experts. Forums can be used to gain access to the experiences of fellow patients without the medical expert being an intermediary in this process. Users thereby benefit from both the expertise garnered during consultations with the medical expert and the experiences of fellow patients (Eysenbach, 2008). Eysenbach and colleagues (2004) already highlighted that providing, receiving, and reading experiences from fellow patients is one of the main functions of social support communities. The current study shows how patients use health forums in a broader context of multiple available sources.

Because websites are easily shared and embedded in online tools such as online forums, the current study found many references to mass communication in general and online sources in particular. Mass communication is likely to be shared with members of the community to sustain and to inform the community through what is called *community building*. Community building creates a feeling of being part of a community and therefore fights the feeling of being alone, which in turn can emotionally support the patient (Bender, Jimenez-Marroquin, & Jadad, 2011).

Limitations and Future Research

We posited that using a hybrid method on natural data could be a tool useful in meeting the challenges faced in studying convergence (i.e., circular process, biased data when trusted on solicited recall data). While we did succeed in analyzing indicators for convergence using forum data, some shortcomings must be acknowledged to advance

future research. While the use of unsolicited data shows its merits, not all aspects of convergence could be studied. First, we could only detect explicit signs of convergence. It would be a safe assumption to imagine convergence occurring in implicit ways as well, such as simply posting a question without stating the events leading up to the post. Furthermore, convergence could only be measured when mass or interpersonal communication led to posting on a forum. However, posting online or reading posts and responding to these posts could lead to convergence elsewhere. By only studying online forum posts on one particular website, these types of convergence could not be measured. While this would result in an underestimation of convergence instead of an overestimation, future research could address these types of convergence. Content analysis (on videotaped consultations) can, for instance, be combined with surveys to investigate patients' (unmet) social support needs when they communicate and to gain insight into how patients use communication sources to cope with their social support needs. The online environment would be a logical place to administer these surveys since this environment does not require actual tracking; instead, log data and prompted surveys could minimize intrusion and reliance on recall. Last, using natural data restricted the possibility to control for differences in personal characteristics of the poster because these variables are not known. Based on previous studies we know that the way patients use online forums changes over time (Verberne et al., 2019). We did not account for these individual differences. Future studies could gather data from multiple forum messages and profiles to extract information on the time of diagnosing, number of posts by the user, and type of disease to gain insight into these concepts.

SML was applied to create a subsample of posts containing signs of convergence. This approach resulted in a significant smaller sample that had to be manually coded. If studies are interested in latent communication concepts such as *social support* needs or motives of patients, researchers should take into account the time and effort needed to code a substantial part of their data as input for the SML, still without a guarantee that these latent construct can be reliably predicted. In an early phase of their study researchers should, based on the number of positive cases per classifier and the initial SML results, decide on the role of SML in their project. Instead of coding a large portion of their data in the hope to obtain reliable classifiers for all constructs, reliable classifiers can be used in an early phase as a filter on the complete dataset to create a small sub-dataset that can be coded by hand.

The current study introduced two possible forms of biases. First, our sample consisted of posts from one forum on a highly trusted Dutch cancer website. Users on this forum might differ from the general cancer population in that they must have the skills to go online and register before using this forum. Furthermore, the fact that these patients opened a forum post could be an indication that they experienced a problem during

a previous communication (e.g., a shortage of information or conflicting information during the consultation with their medical expert). Therefore, the results might not be representative of all cancer patients, and the social support needs and motives found could be an overestimation of the unmet social support needs in this population. However, a complete export of all of the content of a platform with the informed consent of all of the users is still difficult to obtain, thus illustrating the uniqueness of our study. While the reported unmet social support needs might be an overestimation, these unmet social support needs still exist and will likely continue to exist. Therefore, scholars, medical experts, and (cancer) patient associations should work together to make convergence as easy as possible and try to incorporate alternative sources of information into the medical trajectory. For example, a leaflet or a website hosted by the hospital can provide patients with reliable sources but also well-known forums in which patients can exchange experiences and find support.

The second possible bias could have been created during the SML process. The SML algorithm that was used to create a sample of the posts used for the analysis might have caused a bias in the reference category. We manually created the reference category in which no signs of convergence were present. However, it is possible that the original algorithm marked these posts as false positives based on some shared content characteristics. This process might have led to differences between these false positives and the posts without signs of convergence in the corpus (i.e., dataset) that were left out of the analysis. As a result, the reference sample might not completely be representative of the posts without signs of convergence. However, most of the main results are from a comparison between mass and interpersonal communication. These two samples are created by a combination of SML and manual checking; therefore, the above-described bias does not play a role. To overcome this possible bias, future research could either randomly create a sample as the reference category or possibly compare the reference category that was created through machine learning to a random sample before running the analysis.

To conclude, convergence is an important concept that represents the natural flow of patients' information-seeking behavior between and within interpersonal and mass communication. Understanding how patients use different communication channels is essential to improving health care by providing guidance to patients who are trying to fulfill their social support needs. A better understanding of the conditions (i.e., whether the information is discussed and in which way) under which the convergence of interpersonal and mass media results in positive patient outcomes might be the key to enhancing information provision to patients and in turn increasing patients' wellbeing. In doing so, providers should take a pro-active role in discussing online information-seeking with patients and referring patients to the right sources that best meet their social support needs.

Appendix 1

We used SML to train classifiers that could automatically detect the categories established in the manual content analysis. This was done in multiple stages, as we followed an iterative process that checked the performance of the classifiers at each step. The quality of the classifiers was assessed based on precision, recall, and F1 scores for their predictions of cases in which the category was present (i.e., for cases in which the reference to mass or interpersonal media was 1. Precision gives the proportion of the automatically assigned labels that correspond with the human-labeled data. Recall gives the proportion of the true labels that are found automatically. As a result, there is often a tradeoff between the scores of precision and recall; for example, when you assume a higher recall, the chance that some of the recalled data are false positive grows, and as a result, the precision score suffers. F1 scores are the harmonic mean of the recall and precision.

The first sample of SML consisted of 306 manually-labeled posts. The dataset was split into a training set and a test set using an 80-20 split ($N_{train} = 244$; $N_{test} = 62$). Using *Scikit-Learn* (Pedregosa et al., 2011), the data were preprocessed and various classifiers were trained using different algorithms, such as support vector classification (SVC), stochastic gradient descent (SDG), multinomial naïve Bayes (MNB), gradient boosting, and passive aggressive classifier, to evaluate which algorithm had the best performance for each classifier. Given the relatively small dataset, we also assessed whether using a k-fold cross-validation technique (a method in which the data are partitioned in “k” datasets and analyses are performed on the subsets of the data) would improve the performance of the classifiers, however it did not yield positive results and was discarded.

We adopted a gridsearch strategy to search for the best estimation technique and parameter settings. Parameters to be tested included, ngram range, the use of tfidf, class weight (i.e., balanced, none), loss (e.g., hinge, log, modified huber, perceptron, deviance, exponential) and alpha (e.g. 1, 0.1, 0.01, 0,001).

The initial results of the SML showed a good fit for the broad classifiers of the signs of convergence and whether an online or offline mass medium was referenced ($F1_{avr} = 0.89-0.93$). However, this estimated was skewed due to the large number of cases in which the manually coded data was labeled as *not present* (0). Furthermore, few occurrences for the interpersonal media specification classifiers were found; as a result, no suitable SML algorithm could be developed.

To further improve the quality of all the classifiers, an additional random sample of 379 posts was manually coded and divided, again, in a training and test set ($N_{train} = 548$; $N_{test} = 137$). SML was applied again on the larger sample ($N = 685$). The results of the final SML

are displayed in Table 5. The classifiers from the category *convergence: mass communication* and *interpersonal communication*, were deemed reliable enough use. Since the classifiers from other categories showed mixed results, these categories were discarded from further steps and were manually-coded in a later phase instead. Using the classifiers from the category convergence, a subsample of posts likely to contain signs of convergence was created by predicting the complete sample of opening posts.

Predicting the complete dataset of opening posts ($N = 1,708$) showed that 45,14% of the posts were automatically-labeled as having signs of convergence ($N = 771$). To ensure validity, the automatically-labeled convergence classifiers were evaluated by hand. A total of 245 posts (31,78%) did not contain signs of convergence after all and was coded as such. The subsample ($N = 771$) were coded using the codebook by the first author (see table 1).

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Table 5.
Confusion matrix classifiers per category

Concept	Best performing classifier	Recall (1)	Precision (1)	F1 (1)	Decision
Convergence					
Mass media	SDG	0.86	0.92	0.89	Used in the full sample
Interpersonal media	SDG	0.76	0.96	0.85	Used in the full sample
Specification Convergence					
Medical expert	SDG	0.67	0.21	0.32	Not used in the full sample
Others	SDG	0.25	0.17	0.20	Not used in the full sample
Mass media–online	SDG	0.76	0.38	0.51	Not used in the full sample
Mass media–offline	SDG	0.00	0.00	0.00	Not used in the full sample
Motive for Posting					
Conflict	SDG	0.71	0.16	0.26	Not used in the full sample
Shortage of information	SDG	0.00	0.00	0.00	Not used in the full sample
New Question	SDG	0.46	0.11	0.18	Not used in the full sample
Sharing information	SDG	0.86	0.50	0.63	Not used in the full sample
Information on poster					
Disease or treatment information	SDG	0.88	0.82	0.85	Not used in the full sample
Time indication disease or treatment	Passive	0.94	0.73	0.82	Not used in the full sample
Type of Cancer	SDG	0.93	0.65	0.77	Not used in the full sample
Cancer in the surrounding	SDG	0.92	0.39	0.55	Not used in the full sample
Social support needs					
Community building	SDG	0.71	0.71	0.71	Not used in the full sample
Sharing experience	SDG	0.56	0.27	0.36	Not used in the full sample
Asking experience	SDG	0.89	0.91	0.90	Not used in the full sample
Asking information	SDG	0.50	0.07	0.12	Not used in the full sample

4

CHAPTER 4

A Mixed Method Study Investigating the Impact of Talking about Patients' Internet Use on Patient-Reported Outcomes

This chapter is an adapted version of the published article:

Sanders, R., & Linn, A. J. (2018). A mixed method study investigating the impact of talking about patients' internet use on patient-reported outcomes. *Journal of Health Communication*, 23(9), 815-823. doi:10.1080/10810730.2018.1514443

Abstract

This study aims to propose and test a model that provides a more comprehensive understanding of the impact of discussing online health information on patient outcomes. By combining survey data ($N = 160$) and qualitative analysis of video recordings of consultations ($N = 165$) with structural equation modeling, this study explores: 1) whether patients and health care providers talk about online health information and, 2) the impact of talking about online health information on patient outcomes (patient satisfaction, recall of medical information, and medication adherence). Results show that more than half of the patients searched online prior to their consultation. In about half of these consultations (46.81%), the online information was discussed. Patients were more satisfied with the consultation if the online information was discussed during the consultation. Moreover, patient satisfaction was positively related to recall of medical information, but only in patients with whom the online information was discussed. There was no effect found on medication adherence. Results of this study demonstrate the importance of talking about online information during a consultation for improving patient outcomes. Implications for research are discussed.

Introduction

Because of significant changes in today's society and media landscape the internet is an important and easy to use gateway to relevant information before patients consult their health care provider (Abdul-Muhsin, Tyson, Raghu, & Humphreys, 2015; Fox & Duggan, 2013). The internet has brought patients greater access to health information, thereby increasing their autonomy in accessing information to satisfy their information needs (Caiata-Zufferey & Schulz, 2012). Patients are more confident and empowered during the consultation if they went online first (Swee-Lin, Tan & Goonawardene, 2017). Additionally, they report to be more confident in their health care providers' diagnosis once they discussed their online findings. Notwithstanding the potential benefits of internet health information seeking, many concerns have been raised about the impact of online health information on patient outcomes and the patient-provider relationship (Im & Huh, 2017). Online information is often not accurate, may be difficult to understand, and interpretation of information can be overwhelming (Diviani, van den Putte, Meppelink, & van Weert, 2016). Hypothesized negative effects of patients' online information seeking behavior on (patient) outcomes include inappropriate requests for clinical interventions (Eysenbach & Köhler, 2002), higher anxiety, and higher non-adherence rates (Linn et al., 2018).

If and how health care providers deal with online information is expected to be highly relevant to the success of the consultation and consequently, patient outcomes. Unfortunately, knowledge is scarce on whether patients' online health information seeking behavior should be discussed and how this affects patient outcomes. Anecdotal research shows that patient satisfaction can be enhanced or jeopardized, depending on how providers communicate with their patients about online health information (Bylund, Sabee, Imes, & Aldridge Sanford, 2007; Bylund, Gueguen, D'Agostino, Li, & Sonet, 2010). This study adds to this line of research by focusing on other important patient outcomes (e.g., recall of medical information and medication adherence).

Furthermore, most studies in this field use retrospective questionnaires and many results are descriptive (Tan & Goonawardene, 2017). Using retrospective questionnaires has some major drawbacks such as recall bias and could provide inaccurate results (Shiffman, 2009). Additionally, these studies often used a healthy population (Bylund et al., 2007). The current study differentiates itself by analyzing chronically ill patients' and health care providers' actual behavior by combining videotapes of consultations and survey data. This would help paint a more complete picture of the frequency with which patients talk about the information found online but also the impact on patient outcomes.

By adding to this line of research, the following research question is proposed: *how is talking about online information related to patient satisfaction, recall of medical information and medication adherence* (RQ1)? To this end, this study has two aims; 1) to propose a conceptual model that provides a more comprehensive understanding of the impact of talking about online health information on patient outcomes and, 2) to empirically test this model to understand which of these patient outcomes (i.e., patient satisfaction, recall of medical information, medication adherence) are affected by discussing online health information among a chronically ill patient population. The current study focusses on chronically ill patients at the start of their treatment. Health care providers are still patients' preferred, most trusted information source. Nonetheless, many patients use the internet as a source of information in addition to their health care provider (Feathers, Yen, Yun, Strizich, & Swaminath, 2016). Previous research shows that chronically ill patients often use online health information to help them to make treatment decisions (Fox & Duggan, 2013).

Talking about Online Health Information During a Consultation

The internet became an ever-present part of individuals' information lives. Currently, most people have access to, and are becoming comfortable with, using the internet to fulfill their information needs (Tan & Goonawardene, 2017). The changing paradigm in which patients changed from passive to active patients occurred almost simultaneously with the rise of the internet (Wald, Dube, & Anthony, 2007). These active patients fit in nicely with a broader trend in which individuals take a more active role in all aspects of life (Giddens, 1992). In general, patients who seek online health information report a greater understanding of, and ability to manage, their health (Diaz et al., 2002; Imes, Bylund, Sabee, Routsong, & Sanford, 2008; Wald et al., 2007). As a result, patients feel more empowered and are more inclined to be involved in their own health. This may also change the way patients and health care providers talk with each other (Tan & Goonawardene, 2017).

The few studies on this topic examined this along four themes: 1) communication strategies used to talk about the online information, 2) predictors of talking about the online information, 3) facilitators to talk about the online information, and 4) barriers to talk about the online health information (Tan & Goonawardene, 2017). Percentages of patients discussing the online health information with their health care provider vary between 10% and 75% (Corcoran, Haigh, Seabrook, & Schug, 2010; Fox & Rainie, 2002; Shen et al., 2015; Chung 2013). This means that up to 90% of the patients do not discuss online health information with their health care provider. When talking about online information, patients can use direct (i.e., by asking questions or making suggestions) or indirect (i.e., discussing the information found online without revealing that they used the internet) references (Bylund et al., 2007 Sommerhalder, Abraham,

Zufferey, Barth, & Abel, 2009; Kivits, 2006). Facilitators to discuss online health information include having a family member present during the consultation and an open communication style (i.e., health care providers' encouragement to talk about the online information). Barriers include patients' fear of how the health care provider would react (i.e., by "stepping on the doctor's turf") and a closed communication style (i.e., discouragement or neglecting patients' initiation; Bylund et al., 2010; Imes et al., 2008; McMullan, 2006).

Overview of Patient Outcomes

Accumulating evidence indicates that the communication between patients and health care providers plays an important role in impacting patient outcomes. In the current study, a conceptual model will be developed and empirically tested to gain more insight into the impact of talking about online health information patients on three important patient outcomes (i.e., patient satisfaction, recall of medical information, and medication adherence).

Patient satisfaction. Patient satisfaction can be considered a multidimensional concept in which patient satisfaction is a positive attitude or a positive evaluation of health care services (Linder-Pelz, 1982). In this view, patients evaluate different aspects of their care, for example the quality of the communication and the degree to which the health care provider fulfills their needs (Sixma, Kerssens, Campen, & Peters, 2002). When patients seek online health information prior to the consultation, they often expect that they can discuss this information with their health care provider (Diaz, Sciamanna, Evangelou, Stamp, Ferguson, 2005; Sommerhalder et al., 2009). Only a few studies demonstrated that not feeling encouraged to discuss the information retrieved online, or not being able to do so, can lead to dissatisfaction (Bylund et al., 2007). On the contrary, when providers take patients' online health information seeking seriously, this is generally positively related to patient satisfaction (Bylund et al., 2010; Hay et al., 2008).

Recall of medical information. Information about medication is often difficult to understand and remember. It is therefore not surprising that 40-80% of the information provided by the health care provider is immediately forgotten (Kessels, 2003). Recall of medical information can be defined as patients' ability to understand and reproduce medical information (Linn, Van Dijk, Smit, Jansen, & van Weert, 2013). An explanation how talking about online health information affects recall of medical information can be found in a psychological process called *forward encoding*. When patients seek medical information online before the consultation and talk about these topics during the consultation, they will be exposed to two different modalities (i.e., the internet and patient-provider communication). If exposed to multiple communication modalities, forward encoding is stimulated (Voorveld, Neijens, & Smit, 2011). Forward encoding

occurs when a message in the first modality (i.e., medical information found on the internet) ‘primes’ attention to a message in the second modality (i.e., talking about the same online health information during a consultation). This may stimulate interest, curiosity, deeper processing, and consequently, recall of medical information (Dijkstra, 2002). This process is also demonstrated in a review on the use of preparatory tools. This review concludes that talking about patients’ preparations during a consultation can improve recall of medical information (Brandes, Linn, Butow, & van Weert, 2014). In the study of Brandes and colleagues (2014) the patients’ preparation consisted of a Question Prompt List (QPL, a structured list of questions provided hardcopy or online that can be used as a form of preparation before a consultation). The use of a QPL especially improved recall when the health care provider was proactive in talking about the tool (Brown et al., 2011). Thus, if health care providers talk about patients’ preparations, this is expected to result in higher recall rates compared to health care providers who do not talk about patients’ preparatory work (e.g., reading online health information prior to the consultation).

Medication adherence. Medication adherence refers to whether patients take the medication as prescribed as well as whether they continue to take their prescribed medication (Sabaté, 2003). Although non-adherence is directly related to poor clinical outcomes, high health care costs, and poor well-being (Osterberg & Blaschke, 2005), non-adherence rates are high, varying from 30 to 80% (Van den Bemt, Zwikker, & van den Ende, Cornelia, 2012; Vrijens et al., 2012). Recall of medical information is an important first step in achieving successful medication adherence (Linn et al., 2013). After all, if patients don’t remember how, when, and what kind of medication to take, they won’t be able to adhere to their medication. The relationship between recall and adherence is often discussed, but only a few studies researched it. The few studies testing this relationship indeed suggest that recall is positively associated with successful medication adherence (Eysenbach, 2003; Ley, 1988; Linn et al., 2013).

To summarize, we discussed several patient outcomes that might be directly or indirectly affected by discussing online health information during a consultation. To address our first aim, an overview of the aforementioned patient outcomes is presented in a conceptual model. To address our second aim, we will empirically test which of these patient outcomes are affected by discussing online health information. Thus, it might be expected that talking about the online health information patients, results in higher levels of patient satisfaction and better recall of medical information. Research on patient-provider communication also suggests that patient satisfaction with a consultation is directly related to recall of medical information. It can be expected that this relation will be stronger when patients are exposed to multiple modalities and the preparatory work of the patients is acknowledged, i.e., discussed during consultation. Additionally, it is

expected that recall of medical information is directly related to medication adherence. Based on the literature on patient-provider communication and the effects of internet use on patient outcomes, we propose the following conceptual model as displayed in Figure 1.

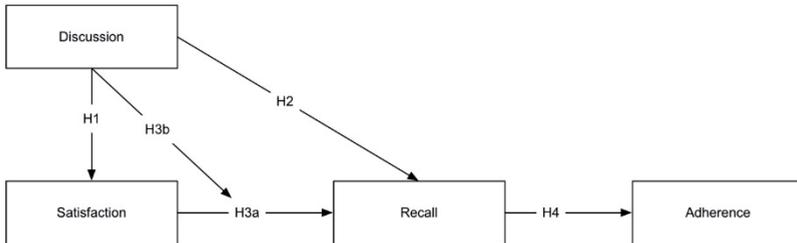


Figure 1. The proposed health information triangulation model.

In testing the model, the following (sub)questions and hypotheses are proposed:

RQ2: How many patients seek online health information prior their consultation?

RQ3: How many patients and health care providers talk about online health information and who initiates the discussion?

H1: Talking about online health information is positively related to patient satisfaction as compared to not talking about it.

H2: Talking about online health information is positively related to recall of medical information as compared to not talking about it.

H3: a) Satisfaction with the consultation is related to improved levels of recall, b) this relationship is stronger when patients and health care providers talk about online information.

H4: Recall of medical information is positively related to medication adherence.

Methods

Procedure and Design

In the Netherlands, as part of usual care, nurses inform patients about their newly prescribed, severe medication (in this case immunosuppressive and biological therapy). In total, eight nurses from six different hospitals participated in the study. Patient inclusion criteria for this study were a) diagnosed with Crohn or Ulcerative Colitis, b) about to start with one of the following medication; Azathioprine, Methotrexate, Adalimumab, Infliximab, 6-mercaptopurine, or 6-thioguanine, and finally c) being able to speak and write Dutch. The Medical Ethical Committee of the University of Amsterdam granted permission for this study, which was supplemented with local feasibility statements.

This retrospective cohort study was part of a larger research project aimed at developing and testing a theoretical and evidence-based tailored multimedia intervention to improve medication adherence in patients with Inflammatory Bowel Disease (IBD). For the purpose of this study, we will only report on measurements that are relevant for our research question. Prior to the consultation, patients completed a questionnaire containing several topics such as demographics, medical information, and online health information seeking behavior (T0). Second, the consultations were recorded on video (T1). Third, directly after the consultation, patient satisfaction was measured (T2). Fourth, a follow-up survey was conducted by telephone, three weeks after the consultation (T3). This survey measured recall of medical information and medication adherence.

Participants

In total 165 patients participated in the survey. From five patients, demographics were missing, therefore they were left out of the analysis. The sample consisted out of 92 women, the mean age was 43. The majority was diagnosed with Crohn's disease. On average, the respondents had been diagnosed for almost twelve years. Of the respondents, the majority was moderately or highly educated (see Table 1).

Table 1.
Patient Demographics

Characteristic Patients ^a	<i>N</i> = 160	%
Gender		
Female	92	57.50%
Age		
<i>M (SD)</i>	43.10 (15.33)	
Type of Disease		
Crohn's disease	101	63.12%
Colitis Ulcerosa	49	30.62%
Other	10	9.09%
Diagnosed in years		
<i>M (SD)</i>	11.61(10.55)	
Range	1.5-47.1	
Educational level		
Low	36	22.50%
Moderate	61	38.13%
High	63	39.37%

^a Data of five patients demographics were missing.

Measurements

Online health information seeking behavior. To assess to what extent patients used the internet before the consultation to search for medical information (T1), patients were explicitly asked if they used the internet to search for medical information (“yes” or “no”). This variable was used to group internet users and non-users for further analysis.

Patient satisfaction. To assess patient satisfaction, a 29-statement scale was used (Linn et al., 2016), measured at T2 (i.e., directly after the consultation). This scale consisted of three subscales. First, satisfaction with the general information provided (e.g., about the disease and treatment; 12 items, $\alpha = .87$). Second, satisfaction with medication support (7 items, $\alpha = .67$). Third, the level of affective communication (10 items, $\alpha = .82$). Respondents were asked to rate statements on a four-point scale, ranging from 0 (very good) to 3 (could be much better), $M = 1.06$; $SD = 1.04$.

Recall of medical information. Recall of medical information was measured using a structured telephone interview three weeks after the consultation (T3). To measure recall of medical information, an adapted version of the Netherlands Patient Information Recall Questionnaire (NPIRQ) was used (Jansen et al., 2008). Patients were prompted to remember the information that the nurses gave about the prescribed medical treatment during the consultation. Examples of questions are “Can you describe the purpose of your treatment?” or “Can you describe the most common side effects of your prescribed medication?” or “Can you describe how you should administer your medication”. All questions were provided with three response options: “not discussed”, “discussed, but I can’t remember the details”, and “discussed, namely...”. With the latter, the patient was invited to write down what (s)he recalled about this topic. Each item recalled by the patient was recorded and checked against the information mentioned by the nurse using an observation checklist (Jansen et al., 2008). Answers to the questions were coded as 0 (not recalled), 1 (partially recalled), or 2 (recalled correctly). In line with previous studies (Jansen et al., 2008; Van Weert, Jansen, Spreeuwenberg, van Dulmen, & Bensing, 2010) a percentage of accurate recall was calculated by dividing the sum of accurate items that were recalled by the total number of items questioned ($M = .51$; $SD = .16$). In total, 19 consultations (13%) were coded by a second coder to calculate intercoder reliability. Intercoder reliability was high (Kappa = .91).

Medication adherence. Medication adherence was measured after three weeks (T3) using one item (Linn et al., 2013). The question was as follows “how closely do you follow instructions when you take your medication (right amount of pills/injections per day/week)”. Patients were asked to rate their medication adherence on a 10-point scale, ranging from 0 (not at all adherent) till 10 (completely adherent), ($M = 8.64$; $SD = 1.53$).

Analysis

To describe how many patients sought online before a consultation about their medication (RQ2), and who initiated the discussion about this information (RQ3), self-reported data (T0) was combined with video recordings of consultations (T1). Consultations were listened to and transcribed in MAXQDA. Based on the survey and the transcripts, four groups were identified: 1) not searched / not discussed, 2) not searched / discussed, 3) searched / not discussed, and 4) searched/ discussed. Patients were included in the analysis if (any combination of) the words *internet*, *Google(d)*, *webpages*, *fora*, *online* or any other internet-related words were mentioned ($N = 60$).

To test the model, first, independent t-test were used to gain insight into the differences between groups (i.e., 3) searched / not discussed and 4) searched/ discussed)) on the variables satisfaction with consultation, recall of medication information, and adherence. To test the hypothesis Structural Equation Modelling (SEM; AMOS 23) was used. This method allowed for testing the whole model at once, instead of separate analysis which would mean a capitalisation on chance.

Missing values were imputed using regression imputation, since only a maximum of 23 items per variable (13.93%) were missing. In total 165 observations were taken into the analysis. The model was tested using the two-step approach in which first the measurement and then the structural part were tested. Since the model would also be tested for the subsample of patients that searched for online health information prior to the consultation ($n = 97$), the model was tested using the derived latent factors from the measurement structure and these were inserted as observed variables in the structural part (Kline, 2016). While it would be more in line with the two-step approach to use the measurement part as input for the structural part, doing this would largely exceed the minimum ratio of 1:10 as discussed by Kline (2016). Using the latent variables directly would only leave eight values to be estimated, thus still satisfying the 1:10 ratio. The measurement model was specified and showed a good fit ($\chi^2(2) = .419$, $p = .811$; $CFI = 1.00$; $RMSEA = 0.00$, $CI90\% [.00, .09]$). The constructs showed good discriminative validity, maximum absolute correlation between factors was $r = .16$.

The following variables were included in the model: talking about online health information, patient satisfaction, and the interaction between these two as independent variables and recall of medication information and adherence as dependent variables (see Appendix 1).

Patient satisfaction. Within the structural equation model, satisfaction with the consultation was inserted in the model using the three sub-scales. While scale 1 loaded strongly on the latent factor, scale 2 ($\beta = .66$; $R^2 = .43$) and scale 3 ($\beta = .69$; $R^2 = .47$)

showed lower standardized estimates compared to the standard of Kline (2016). Deleting these items resulted in significant lower model fit and loss of much data, therefore they were included in the sum scale that was created.

Recall of medical information. Within the structural equation model, this observed variable was inserted as a one item latent factor with an assumed error margin of 10% (variance of error term = .3). This margin was chosen by first taking the inter-coder reliability (.9) as starting point and then by exploring whether changing the error margin, and thus the error term variances changed the model fit and estimates significantly, which it did not.

Medication adherence. Within the structural equation model, this single item scale was inserted as a one item latent factor with an assumed error margin of 10% (variance of error term = $1.11 * .10 = .11$). This margin was achieved by taking the assumed measurement error of the variable *recall* and then exploring whether changing the error margin, and thus the error term variances changed the model fit and estimates significantly which it did not.

Interaction satisfaction and talking. To test the moderation of the variables satisfaction and talking about the online health information on recall of medical information, a moderation variable was made by making a new variable (called *interaction*) consisting of the calculation: satisfaction * discussion ($M = .34$; $SD = .63$). The dataset was ill-scaled and recall was therefore transformed. The minimization history showed no errors, with a steady decline across diameter, condition and F without too many tries or negative eigenvalues. No Haywood cases appeared.

Results

Talking about Online Health Information

First, we explored how many patients sought online health information prior to their consultation, how many patients and health care providers talked about it (RQ2) and who initiated the discussion about this information (RQ3). In total, 57.00% ($n = 95$) patients searched for medication-related online health information prior to the consultation. In 46.81% ($n = 44$) of the consultations with these patients, the online health information was discussed. Overall, the discussion of online health information was almost evenly initiated by patients ($n = 33$; 55.00%) and health care providers ($n = 27$; 45.00%).

The Health Information Triangulation Model

To test the hypotheses, the proposed conceptual model was only tested for patients who searched online health information prior to the consultation. Hypothesis 1 predicted that talking about patients' online health information was positively related to patient satisfaction. Hypothesis 1 was confirmed: there was a significant relation between the discussion of online health information during consultation and patient satisfaction ($B = -.69, p < .001$). Meaning, patients who talked about the online health information during consultation were more satisfied with the consultation ($M = .86; SD = .61$) compared to patients who searched online but did not talk about it ($M = 1.30; SD = 1.13$), $M_{diff} = -.43, p = .041, d = .48$). Hypothesis two predicted that talking about patients' online health information was positively related to recall of medical information, compared to not talking about. Hypothesis two was rejected. There was no significant relation between discussion of online health information and recall of medical information ($M_{diff} = .12, p = .310$). Hypothesis three predicted that patient satisfaction was related to improved level of recall of medical information (3a), and that this effect was stronger when patients and health care providers talk about patients' online health information (3b). Hypothesis 3a was rejected, there was no significant direct relation between patient satisfaction on recall medical information ($M_{diff} = -.13, p = .270$). Hypothesis 3b was confirmed with a marginally significance level: for patients discussing online health information, higher satisfaction with the consultation was related to higher recall of medical information, compared to not discussing it ($M_{diff} = .32, p = .054$). Hypothesis four predicted that recall of medical information was positively related to medication adherence and was rejected. There was no significant relation between recall of medical information and adherence ($M_{diff} = .01, p = .922$). The outcomes are displayed in Table 2 and Figure 2.

Table 2.

Means per condition on patient satisfaction, recall of information and medication adherence

	Internet use			Group			
	Overall	No	Yes	1	2	3	4
Satisfaction*	1.06	.99	1.10	.98	1.09	1.30^b	.86^b
Recall	.51	.48 ^a	.53 ^a	.47	.51	.53	.52
Adherence	9.15	9.14	9.16	9.21	8.86	9.21	9.15

^a $M_{diff} = .05, p = .007$;

^b $M_{diff}(78.99) = .43, p = .029$.

^c lower means indicates higher.

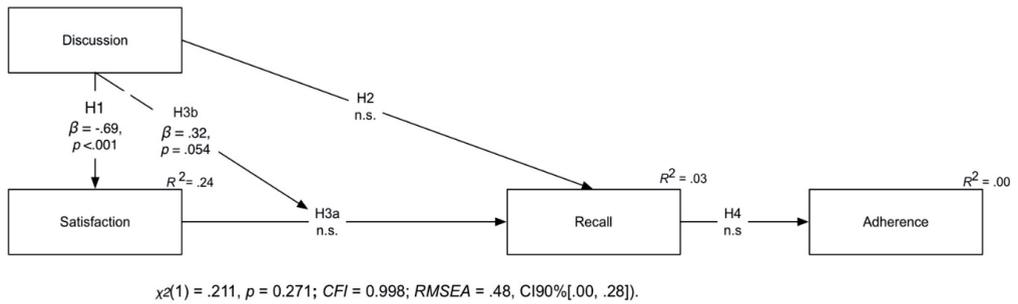


Figure 2. Hypotheses with significant standardized regression coefficients.

Discussion

This study aimed to gain more insight into how talking about online health information was related to patient outcomes. We proposed and tested a conceptual model that aimed to provide a more comprehensive understanding of the impact of talking about online health information on patient outcomes (i.e., patient satisfaction, recall of medical information, medication adherence). More than half of the patients searched for online health information prior to the consultation. In around half of these consultations, online health information was discussed, initiated evenly by patients and health care providers. Results also showed that, if patients and health care providers talked about online health information, this resulted in higher patient satisfaction. Furthermore, satisfaction was positively related to recall of medical information, but only in patients who discussed the online health information during the consultation. Based on the results of our study we propose the Health Information Triangulation Model (see Figure 3).

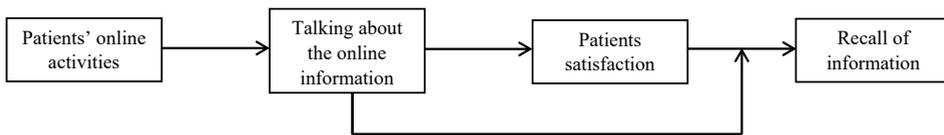


Figure 3. The Health Information Triangulation Model.

Only half of the patients talked about the online health information with their health care provider. These results are in line with previous research indicating that percentages of patients who (intended to) discuss the online health information vary between 10% and 75% (Corcoran et al., 2010; Fox & Rainie, 2002; Shen et al., 2015). However, it is possible that patients in our sample discussed online health information without disclosing the source (i.e., indirectly). According to a study among cancer patients, almost half of the patients indirectly disclose online health information (Bylund et al., 2007). As

we analyzed recordings of actual consultations, we only coded if patients directly disclosed online information. Possibly, more patients discussed online health information without us being able to code this. Future research could supplement recordings of consultations with self-reported measurements (i.e., interviews) in which patients are asked which online health information was cited during the consultation.

In a non-disease-specific patient population, it was found that health care providers' disagreement with online health information resulted in lower patient satisfaction (Bylund et al., 2007). On the contrary, taking the information seriously was related to greater patient satisfaction (Bylund et al., 2010). Our results demonstrate that not the communication style but the act of discussing online health information improved patient satisfaction. It might be that the effect on patient satisfaction is stronger for certain communication styles. Because of a lack of power, we were not able to differentiate between these different communication strategies (e.g., taking the information seriously). Future research should experimentally test the effects of different communication strategies. This would not only allow us to gain more insight into the possible different effects of these communication strategies on patient outcomes, it would also allow us to pinpoint causalities.

In today's information environment, patients often combine advice from different sources (Harvey, Harries, & Fischer, 2000). In relation to medical information, health care providers and the internet are the most common sources of conflicting information. Previous research demonstrated a negative effect of receiving conflicting information on medication adherence (Carpenter et al., 2013). As we did not analyze how the online health information was discussed (e.g., repeated by the nurse or corrected in the case of inaccurate information) experimental studies should be conducted to explore how repeating or correcting online health information would affect recall of medical information and medication adherence. We used forward encoding to explain the effect of talking about online health information on recall of medical information. Our findings suggest that forward encoding (Dijkstra, Buijtel, & van Raaij, 2005) is a useful psychological process that should be considered when analyzing the effects of the use of different modalities in health communication. We however, did not measure forward encoding. Forward encoding should be included in future research to exclude other processes or mechanism such as encoding variability (i.e., the information will be encoded in a more complex manner when patients are exposed to the same message in a variety of media (Voorveld & Neijens, 2015)) that might contribute to the effect of multiple exposure on recall of medical information.

We did not find an effect of recall of medical information on medication adherence. A possible explanation can be found in the way we measured adherence. Rossiter (2002)

proposes that if the behavior can be operationalized as concrete, it is not necessary to use multiple items to measure this construct. Thus, we can assume that the item used to measure adherence might be accurate; however, other measurements such as refill data or electronic monitoring may enhance the validity of our findings.

A limitation of this study is that we measured patient's online health information seeking behavior before the consultation which might have primed patients to talk about their online seeking behavior. We limited this possibility by taking the following precautionary measures. First, patients were blinded to the actual purpose of this study. Second, as this study was part of a larger project we not only included patients' online health information seeking behavior in the survey but also other measurements. Third, we checked whether the recordings could be considered an accurate reflection of an average consultation. According to the providers who were interviewed afterwards, the taped consultations were usually reflecting an average consultation. However, possible priming effects could not be excluded and future research should control for possible testing effects.

The proposed model could be extended with factors such as the type of information searched and the attention paid to the discussion of online health information. First, in the current study it remains unknown which online health information patients encountered prior to the consultation. When seeking online, patients can use information found in peer-reviewed journals or join an online discussion forum. These sources differ in function, content, credibility and needs fulfillment. For example, information found in a peer-reviewed journal might fulfill patients' information needs while participating in a forum fulfills patients' need for support (Sanders, Linn, Araujo, Vliementhart & Van Weert, 2020). These different sources might also affect the consultation differently. Imes and colleagues (2008) for example showed that the type of information (e.g., low quality information) found affects patients' intention to discuss this information with their health care provider. Moreover, in the current study, talking about online was treated as a dichotomy. It can be argued that talking about online health information is a continuum, ranging from "no attention" to "a lot of attention" (Im & Huh, 2017). As we measured online health information seeking with only one dichotomous item, we neither have data on the type of information nor on the attention paid. Future research should take measures into account that capture the inherent complexity of online health information. By doing this, more variation will be considered, which could possibly lead to a more detailed picture.

Conclusion

Theoretically, the current study has been among the first that integrates two previously distinct bodies of research: patient-provider communication research and the literature on internet seeking behavior. In doing so, we identified promising avenues for future

research in health communication. By combining survey data and qualitative analysis of video recordings of actual consultation with structural equation modeling the Health Information Triangulation Model is proposed.

Appendix I.*Model correlation matrix with mean and standard deviations*

Variables	1	2	3	4	5
1. Discussion	1.00	-	-	-	-
2. Satisfaction with consultation	-.09	1.00	-	-	-
3. Recall of medication information	-.07	-.09	1.00	-	-
4. Interaction	.72	.23	.01	1.00	-
5. Adherence	-.09	-.08	.11	-.14	1.00
Mean	.36	1.06	.51	.34	8.64
SD	.48	1.04	.16	.63	1.53



CHAPTER 5

Summary & Discussion

Summary

Cancer is the second most common disease, and the incidence of cancer is rising. Cancer patients have many cognitive and affective needs (hereafter called “social support needs” unless otherwise specified). Currently, the two primary sources of information are medical experts and online health information. To fulfil their social support needs, patients often use a combination of these sources. This dissertation aimed to investigate what social support needs patients seek to fulfil by combining multiple media sources (i.e., convergence), how these social support needs influence online health information use, and the effects of convergence on patient outcomes (satisfaction, recall, and medication adherence). To answer these questions, three different empirical studies are featured in this dissertation.

Online Content and Patients’ Needs

In Chapter 2, I investigated how content from different online health information platforms is related to cancer patients’ social support needs. Online health information has previously been used as an umbrella term encompassing different online sources such as blogs, forums, and medical libraries. In this chapter, a hybrid method combining qualitative research and a computational social science method was used to examine the social support needs of cancer patients and the content available online while distinguishing between different online platforms. I divided the online health information content into peer- and expert-generated content. Peer-generated content is written by laypersons such as patients whereas expert-generated content is written by professionals with medical training. To have a strong theoretical foundation, a literature review was conducted to develop an initial model of patients’ social support needs. This model consisted of social support needs ranging from patients’ basic cognitive and affective needs to social support topics that are identifiable in online content. Then, I matched the content to patients’ social support needs to investigate which social support needs were addressed online. Topic modelling on content ($N_{posts} = 52,990$) from two different peer-generated platforms (i.e., blogs and forums) and two different expert-generated platforms (i.e., a medical library and question and answers) revealed 25 social support topics. The social support topics from the topic modelling were matched to the social support needs originating from the literature review. Overall, the initial model of patients’ social support needs adequately represented the content found online. However, one additional social support category, namely, *sharing status*, needed to be included. In this category, patients disclosed how they are currently doing, disclosed how they experienced the situation in the past, or shared their experiences with a relative diagnosed with cancer. Differences in content between and within platforms were found. Content on peer-

generated platforms mainly focused on interaction on emotional support topics whereas the content in expert-generated platforms mainly focused on informational support topics. Within peer-generated platforms, I found that on blogs, patients generally write about how they are doing at that moment; whereas on forums, patients discuss their previous experiences.

In this chapter, I show how multidimensional online health information is and provide a concrete method to differentiate between peer- and expert-generated health information. Building further upon the idea of different online health information platforms, I show how the content on these platforms targets different social support needs. Using these insights, patients can more easily find, and be better guided to, appropriate content based on their social support needs.

5

Intra- and Intermedium Convergence

In Chapter 3, I investigated the concept of convergence. Convergence refers to a sequence of mass and/or interpersonal communication channel usage to fulfil a user's (new) social support needs. Specifically, I investigated the frequency of reported convergence, how convergence affected what posters wrote in forum posts, the motives they had for posting, and the social support needs they were seeking to fulfil by starting a forum thread. As in the previous chapter, a hybrid method was used, but this time supervised machine learning in combination with manual content analysis was used. With this method, I gained insight into the levels of convergence between mass and interpersonal information sources (intermedium convergence) and convergence within mass information sources (intramedium convergence) on forum opening posts. A total of 1,708 forum opening posts were analysed. Nearly one-third of these opening posts contained signs of convergence. Posts containing mass media references disclosed less personal information about the poster. Instead, they were often used to enhance the online community or to share experiences (compared to posts without convergence). Again, compared to posts without convergence, the writers of posts that included interpersonal media references contained more disclosure of personal details and were more likely to ask fellow forum users about their experiences. When comparing posts containing signs of convergence, the posters that included interpersonal media references reported less shortage of information, disclosed more information about their disease, and were more active in asking fellow forum users for their experiences compared to posters that included references to mass media.

In this chapter, I build upon the concept of convergence and extend the definition of this concept. I also applied this concept to online forum data and showed how patients seek to fulfil different social support needs based on previous communication effort. I

thereby highlighted the unique feature of peer-generated platforms to inquire and share personal experiences.

Discussion of Online Health Information and Patient Outcomes

In Chapter 4, I used a combination of survey data ($N = 160$) and recordings of consultations ($N = 165$) to advance our understanding of the effect of discussing online health information on patient-reported outcomes. Chapter 4 had two goals. First, I was interested in whether patients and medical experts discussed online health information. Second, I was interested in the effects of the discussion of online health information on patient satisfaction, the recall of medical information, and medication adherence. Of all patients included in the study, approximately 50% searched online for information before their consultations. Approximately half (46.81%) of the patients who searched for online health information discussed this during their consultations. When I explored the effects of discussing online health information, I found that patients were more satisfied with their consultations if the information was discussed. In turn, patient satisfaction was positively related to the recall of medical information but only among the patients who discussed the online health information during their consultations. No relation was found between the discussion of online health information and medication adherence. Based on these results, the health information triangulation model is proposed to guide future research into the effects of online health information on patient-provider communication and patient outcomes.

By using a survey and recordings of actual consultations, in this chapter, I showed how intermedium convergence of online health information and patient-provider interaction can have implications for patient outcomes. I thereby highlight the importance of discussing online health information and the possible benefits of convergence.

Discussion

This dissertation aimed to answer the following questions: what social support needs do patients fulfil by combining multiple media sources (i.e., convergence), how does convergence influence online health information use, and what are the effects of convergence on patient outcomes? Chapter 2 and Chapter 3 provide a more precise idea of what online health information is and how online platforms and their content are related to patients' social support needs. Furthermore, we gained insight into how patients are actively seeking to fulfil certain social support needs by using peer-generated platforms. Regarding combining multiple media, Chapter 3 and Chapter 4 helped us to see how patients' social support needs differ depending on other sources they have used. Furthermore, in the last two empirical chapters, I studied convergence in two settings: a peer-generated online forum and medical consultations. First, I will further discuss online health information and the fulfilment patients' social support needs. Second, I delve deeper into the concept of convergence.

5

Social Support Needs Fulfilment and Online Health Information

I started the introduction of this dissertation with a discussion of the risk society with diminishing central powers and the critical and active actors that live in such a society. The results found in Chapters 2 and 3 highlight the active role patients take in seeking information about their health outside of a consultation room. Patients not only actively seek information online but also take an extra step by creating content. As such, a clear distinction in Chapter 2 could be made between peer- and expert-generated content.

In Chapter 2, I matched the content available on multiple platforms to obtain a better understanding of patients' social support needs to the model of patients' social support needs. Most of the social support needs known from the literature that patients experience in the offline setting appeared to also exist in online health information seeking. However, in the online setting, the social concept of peer-to-peer communication plays an important role, which is visible in the concept of *sharing patients' status*. Sharing status entails the need of patients to share their current status (online), the need to share past experiences (as a response to questions of fellow patients) or to share the experiences of living with a relative who was diagnosed with cancer. Here, the availability, asynchronicity, anonymity, and large reach of the internet play an important role. Patients can search for peer-generated content such as experiences on existing forums at any time, and they can create a new forum thread to which other patients can respond at any time. Peer-to-peer interaction has been studied before in multiple settings, e.g., cancer, addiction, and pregnancy (e.g., Gooden & Winefield, 2007; Klemm et al., 2003; Seale, Charteris-

Black, MacFarlane, & McPherson, 2010). The results of these studies show that being in contact with peers and asking and answering questions can have a supporting effect and add to the reader's wellbeing (Batenburg & Das, 2014; Sinha, Porter, Wilson, 2018). Based on the outcomes of the analysis performed in Chapter 3, we see that patients miss the experiences of fellow patients after seeing a medical expert. They then turn to a peer-generated platform such as a forum and inquire about these experiences to fulfil their social support needs. This result is in line with the optimal matching theory, which predicts that patients actively choose a medium that likely fulfils their needs (Cutrona, 1990). The patients in my sample thus seem to know to which platform they need to turn to with those specific social support needs.

Combining the findings of Chapter 2 and Chapter 3 shows how patients are deliberately seeking the right content for them on the right platform. Reading the experiences of others on peer-generated platforms seems to fulfil the emotional needs of patients.

Theoretical Contribution to Social Support Needs Fulfilment and Online Health Information

In Chapter 2, the model of patients' social support needs brings together the various ways in which patients' social support needs were met. The most basic operationalization of needs can be found in the typology of cognitive and affective needs (Bensing & Verhaak, 2004; Coulson, 2005). Additionally, I used several classifications containing more specific needs such as the social support behaviour code (Cutrona & Suhr, 1992) and the typology of Rutten et al. (2005). These classifications showed overlap but also distinctions between the concepts. The model of patients' social support needs incorporates these typologies into one framework. This model can be used as a blueprint for future studies investigating or comparing social support needs on other online platforms (e.g., *Twitter*, *Facebook*, etc.).

This model also acts as a tool to demonstrate the inherent differences between online health information platforms. Most research involving online health information focuses either on the predictors or the outcomes of using online health information. Often, this research treats online health information as a unidimensional concept. However, I show in Chapter 2 that even within one website, multiple peer- and expert-generated platforms exist and that these platforms fulfil different social support needs. This shows how diverse online health information could be. As a consequence, research should specify what type of content patients read since this can affect multiple outcomes such as unfulfilled social support needs, the need to discuss the information with a medical expert, the recall of medical information, etc. This is further highlighted in Chapter 3 where I show that depending on the previously used source of information, the motive for using a forum and the needs patients seek to fulfil by posting on a forum differ. I therefore urge future

researchers to be more specific in questioning what types of information patients read and what types of platform(s) these patients have used to further accumulate knowledge.

Convergence and Patient Outcomes

My second aim was to investigate how the use of different information sources impacts each other. I studied the concept of convergence in both an online (Chapter 3) and an offline setting (Chapter 4). The notion that the use of sources influences each other is not new. It has been suggested that interpersonal and mediated sources interact in sequence with each other (Lupton, 2012). Based on Chapters 3 and 4, I conclude that communication with a medical expert can indeed influence online health information seeking and that online health information seeking can influence communication with a medical expert. However, online health information also influences the use of other online health information sources.

Two lessons can be drawn regarding convergence. First, patients' social support needs and media usage are influenced by their previous communication efforts. We observed that patients' needs when using peer-generated platforms were dependent on whether they used mass media (e.g., the internet) or interpersonal media (e.g., their medical expert) before going online (again). While I did not measure this, it is highly likely that the needs of the patients in the offline world (i.e., consultation rooms) are also often influenced by media use before consultations. The notion of complementary media use of traditional and new media has been suggested previously, and it also seems to be the case here (Dutta-Bergman, 2004). For example, as was found in Chapter 3, patients who used an interpersonal communication source (often a medical expert) gave little indication that they had a shortage of information. However, they still went to peer-generated platforms to inquire about experiences from fellow users. Based on the previous literature, there are indications that emotional and social needs are often not met by providers (Chawla et al., 2016; Ha, Anat, & Longnecker, 2010). This notion seems to be highlighted by my results. Thus, while after their consultations, most (cognitive) needs seemed to be fulfilled, and patients continued to look online for complementary information in the experiences of other users to fully fulfil their (emotional) needs. To highlight the importance of sharing status and the matching emotional support, this concept was added to the framework I proposed in Chapter 2.

Second, the discussion of online health information with medical experts (i.e., intermedium convergence) influences patient outcomes. Based on previous research, there was an expectation that online health information influences communication with medical experts (Nguyen et al., 2019; Osei-Frimpong et al., 2018; Tan & Goonawardene, 2017). While many patients search online before their consultations, they often do not discuss the information they have found online during their consultations (Chung, 2013;

Corcoran, Haigh, Seabrook, & Schug, 2010; Fox & Rainie, 2002; Linn, Schouten, Sanders, van Weert, & Bylund, 2020; Shen et al., 2015). In Chapter 4, I examine the signs of convergence between online health information and patient-provider communication. We found that almost a quarter of the patients engaged in intermedium convergence and thus discussed the online health information they found with medical experts. Based on the results, it can be argued that a lack of stimulating intermedium convergence is a missed opportunity since patients who engage in intermedium convergence benefited from this in terms of satisfaction and recall. Again, the complementary nature of both sources of information presents a great opportunity. The discussion of patients' health information-seeking behaviour allows us to answer the remaining questions and uncertainties, co-create an understanding between medical experts and patients by exchanging opinions and knowledge, and even acknowledge the effort patients put into searching online.

Theoretical Contribution Convergence and Patient Outcomes

In Chapters 3 and 4, I combine multiple sources of information, which I call convergence. We can see how these sources influence each other and even patient outcomes. However, the notion of convergence is not entirely new. Kreps (2017) proposed a two-type theoretical definition of convergence (Kreps, 2017). Type 1 convergence “focuses on the use of the information accessed through digital mass media and its subsequent discussion in interpersonal encounters” and has several iterations of this type of convergence (Kreps, 2017, p. 519). Type two convergence “pertains to the conduct of interpersonal and peer discussions about health-related issues in virtual discussion spaces of various kinds” (Kreps, 2017, p. 521).

Since that article, to the best of my knowledge, no empirical research has investigated mass and interpersonal media convergence and its effect on patient outcomes. As a result, it remained a theoretical idea. I investigated the notion of convergence and adopted the definition of convergence by including the concepts of inter- and intramedium convergence. By operationalizing convergence as a combination of interpersonal and mass media sources (intermedium convergence) or as a combination of either mass media sources or interpersonal sources (intramedium convergence), the convergence process can occur online and offline and can include any combination of sources. In the definition of Kreps (2017), there was a fixed order of sources in convergence type one: a patient looks up online health information and then discusses it with a medical expert. I examine this type of intermedium convergence in Chapter 4. However, in my definition, this combination can also be inverted (medical expert and then online health information), as we saw in Chapter 3. This particular sequence of mass and interpersonal communication was not included in the original definition of type 1 convergence. Broadening this definition has implications for how the results should be interpreted. For example, I study intermedium convergence by examining references

made to interpersonal communication in forum posts. According to the definition of Kreps (2017), this example would simply be labelled as a virtual discussion (type two convergence). However, the fact that an interpersonal communication effort has occurred is then neglected as it is labelled an online discussion. In my definition, I disregard the sequence and I consider this as intermedium convergence. In summary, type one convergence is always intermedium convergence, type two convergence can contain both inter- and intramedium convergence. This distinction in type two convergence is added by my definition. By broadening and specifying the concept of convergence, it becomes possible to systematically study convergence and its effects both online and offline across multiple populations (e.g., patients, consumers, and experts) and in any order in which various communication channels are used. This broader conceptualization of convergence should provide us with guidance in the upcoming field in which the effects of multiple information sources are studied.

Methodological Contributions

Natural Data

Throughout my thesis, I used natural unsolicited occurring data, possibly in combination with a survey. Natural unsolicited data are data that exist without the intervention of researchers (Shah, 2015). As I wrote in my introduction, with the rise of the internet, increasingly more data that can help us understand human behaviour and, in the case of this dissertation, how patients' social support needs change through the use of communication channels, are becoming available. Natural unsolicited data are less likely to be influenced by experimenter effects and social desirability biases in ways that survey and experimental data are affected (van Atteveld & Peng, 2018). Furthermore, it is also possible to avoid problems occurring due to recall bias or estimation problems on the part of the respondent; thus, in some cases, naturally occurring data can provide a better estimation of the concepts of interest (Araujo, Wonneberger, Neijens, & de Vreese, 2017). As a result of this increase in available data and the possibility of analysing these data, increasingly more research is using these data using linguistic approaches, machine learning, and cluster analysis (Bidmon, 2020; Chen, 2012; Chen, 2020; Greaves et al., 2013).

However, natural unsolicited data can also be retrieved from the offline world. For instance, natural occurring events such as consultations with a medical expert are also an example of naturally occurring data. While it is often difficult to collect these data, they can provide useful insights, especially when coupled with quantitative data gathered at the event itself.

By analysing data from kanker.nl using computational social science methods, as well as discussions between chronic patients and their care providers, this dissertation provides insight into the motives and social support needs of website users and the behaviour of patients and health care providers when the subject under study is occurring. I also show how computational social science methods can be coupled with a strong theoretical foundation to aid the interpretation of the (unsupervised) machine learning results (Chapter 2) or how computational social science methods can be coupled with traditional manual coding when the concepts become latent to be reliably estimated by machine learning using a smaller dataset (Chapter 3). Both approaches do not use machine learning on their own but they incorporate these techniques in a broader research approach to come to theoretically and empirically relevant insights. Both issues will be discussed in more detail now.

Addressing the Limitations of (un)Supervised Machine Learning and Naturally Occurring Data

Although these data provided valuable and innovative insights, shortcomings must be acknowledged. For example, unsupervised machine learning can often limit itself to explorative analysis and post hoc interpretations of relatively easy theoretical constructs. To overcome this challenge, I coupled computational analysis of Chapter 2 with an a priori defined theoretical model that bridges latent needs to identifiable topics. In other words, I linked online content to abstract needs via the model of patients' social support needs. I also showed how to use a theoretically defined framework to interpret unsupervised machine learning outcomes. This allowed me to theoretically but yet open-mindedly map the online context.

It is also important to find ways to move beyond easily identifiable concepts when using machine learning techniques. Instead of using solely machine learning or manual content analysis, a combination in which the strengths of both approaches are used can be made. For example, in Chapter 3, I sought to automatically code convergence, motives, and social support needs in forum opening posts. While I could reliably detect references to other mass and interpersonal media, it was much more difficult to detect social support needs and motives due to very different wordings in which these social support needs and motives were expressed. This resulted in manually coding more text than planned. In these cases, I would suggest future research to use a machine learning algorithm to filter the relevant content from a large corpus and manually code the remaining concepts. By using this hybrid form, we can study more latent and theoretically rich concepts.

Practical Implications

The results of this dissertation provide multiple suggestions to improve the practice. As shown in Chapters 3 and 4, there is a patient group that knows where to find the right information to fulfil their needs and is able to integrate that information in their consultations. However, we know from the literature that there is a large patient group that has difficulty finding quality information or handling information overload (Cline & Haynes, 2001; Gray et al., 2005). That population is not part of the data analysed in this dissertation, but especially they could benefit from the insights of this dissertation. To do so, first, I will discuss how online health information could be integrated into communication by medical experts. Second, I suggest several ways to improve the organization and retrieval of online health information.

5

Online Health Information Integration in Communication During Consultation

In this dissertation, I showed that a majority of the patients searched for online health information and that searching for information in one source can influence the use of a subsequent communication channel. Since I showed that even the relatively simple integration of online health information into a consultation leads to improved patient outcomes, the importance of integrating health information seeking in the consultation should be acknowledged and enhanced by medical experts. This dissertation also showed that patients often need to share or read the experiences of fellow patients. A medical expert could take a more active role in guiding patients to platforms that could fulfil those social support needs. This guidance could help patients who lack the skills to find these platforms themselves to still fulfil their social support needs. A next step would be to train medical experts to discuss online health information in a supportive way.

Optimizing Data Retrieval and Searching

Another step that could be taken to help patients find the right information is by improving the way online health information is displayed and can be searched. Of course, searching and finding the right information continues to be a challenge, especially when the amount of information available grows. The *model of social support needs* and the algorithm that is able to detect the social support needs from Chapter 2 can help in this regard. The model of social support needs follows the natural flow of patients from broad needs to specific needs (Wilson et al., 2002). By using this model as a blueprint for a website, the website becomes more intuitive for a patient to navigate. Furthermore, the algorithm that is developed can help patients find the right information based on their social support needs instead of requiring them to enter keywords in a search function. By grouping and highlighting texts from multiple platforms, patients can see the information that matches their social support needs. For example, a patient seeking how to handle

side effects expresses that social support need in a search function. As a result, the website can show, in one overview, expert-generated information about the side effects from a medical library and peer-generated information from a forum or blog where stories, questions and answers from fellow patients addressing the same question are available. Finding the right type of high quality information can mean a head start for the patient in the process of integrating the information found online in a consultation and ultimately positively influencing satisfaction with a consultation (Diaz et al., 2005; Sommerhalder et al., 2009). These positive results might be a key reason for medical experts to invest time and energy into discussing the online health-seeking behaviour of patients.

Limitations and Suggestions for Future Research

The current dissertation has limitations. I will discuss the most important limitations and suggest how future research could counter these limitations.

Data Originating from Online Health Information Finders

Most of the data used in this dissertation originate from users who know how to search for online health information or are active and skilled enough to open a forum post to ask their questions. As already highlighted, not everybody knows how open a forum post. I offered some suggestions to improve the access to online health information in the practical implications section. However, we also need more insights into how detailed user characteristics influence the use of different platforms of a website. In this way, we could identify more easily which patient is likely to find what type of content. Then, we could tailor the guidance of some patients to direct them to content that could fulfil their social support needs on platforms they are less likely to visit. So more patients can benefit from the rich content that is available on multiple online platforms. Next, I will discuss how these patients can be reached.

Tracking Patients

Technology enables researchers to track patients over time. This not only captures the online health-seeking behaviour of patients in a natural setting but also allows researchers to see how patients obtain information from multiple platforms, identify user patterns, and determine whether this online behaviour influences convergence. Specifically, opt-in questionnaires (using pop-ups) could be placed at places where online health information is frequently obtained (this includes multiple platforms such as validated health websites; forums such as *Reddit*; or social media channels such as *Facebook*, *Twitter*, and *YouTube*) to recruit participants, identify their characteristics, track their behaviour, and assess their motives and social support needs. This allows researchers to know which types of patients are searching for certain content, which keywords they use to search, their motives, and

to what degree that content fulfils their social support needs. Based on this information, the study could follow patients either online (e.g., what online content do they gather) or offline (e.g., do they visit a medical expert and how do they use the information obtained online). Using a combination of tracking data and follow-up questionnaires, we could capture the process of need specification, information seeking, and need fulfilment via multiple mass media and interpersonal sources.

Content, Motives, and Discussion Style

While I started researching convergence in a medical setting, many questions remain unanswered. For example, the results of this dissertation do not provide insight into the content patients retrieved before their consultation. Furthermore, the motives for patients going online remain unknown. Previous research suggests that some patients only search for online health information for their own use and thus have no intention to discuss this information with a medical expert (Linn, van Weert, & Bylund, 2021). Those patients are likely to react differently to a medical expert who is not willing to discuss online health information compared to a patient who wants to discuss the obtained information with their medical expert. Last, how medical experts discuss online health information could have a moderating effect on the associated patient outcomes. For example, a medical expert dismissing online health information could leave an internet-informed patient unsatisfied. In Chapter 4, the concepts of motives, content, and discussion style are omitted. For future research, I suggest an experiment in which these factors can be manipulated so we can understand the underlying mechanisms even better. For example, the social support needs of patients can be manipulated by highlighting the emotional needs of being sick (e.g., seeking ways to handle anxiety) or by highlighting the informational needs that arise while being sick (e.g., want to know if and how insurance covers the expenses of tests). Then, the content could be either factual expert-generated or supportive peer-generated. Last, the discussion style of the medical expert can be manipulated by letting the medical expert use supportive or unsupportive wording for online health information in general or the seeking behaviour of the patient in particular. Insights from such a study would not only help researchers understand how these concepts influence each other, but it would also allow us to be more concrete in our advice to medical experts to integrate online health information in their consultations.

Final Thoughts/Conclusion

The main contribution of this dissertation is that it provides an overview of different platforms and the content on these platforms, investigates how patients actively use a combination of platforms and channels to fulfil their social support needs, and it proposes

two frameworks that summarize the social support needs patients fulfil online and the variety of effects convergence has on patient outcomes.

Searching for online health information and using online health information does not occur in a vacuum; instead, it is influenced by other communication sources used by patients. The interdependency of different health information sources should receive more attention, both in practice and in research. While some patients already know how to use all the platforms that exist, patient groups who have problems finding the right type of information online should be guided better in the future. Better integration of online health information in consultations and a more intuitive online context can be the first step towards a better integrated approach.



ADDENDUM

References

Nederlandse Samenvatting

Dankwoord

Author Contributions

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Nederlandse Samenvatting

Kanker is de op twee na meest voorkomende ziekte, en helaas stijgt de jaarlijkse incidentie nog steeds. Patiënten die gediagnosticeerd zijn met kanker kunnen verschillende cognitieve en affectieve behoeftes hebben (deze worden hierna samengevat onder de term “behoefte aan sociale ondersteuning”, tenzij er speciaal naar een specifieke behoefte wordt verwezen). Tegenwoordig zijn de arts en het internet de twee belangrijkste informatiebronnen voor patiënten. Om de behoeftes aan sociale ondersteuning te vervullen gebruiken patiënten vaak meerdere bronnen en combineren de informatie uit deze bronnen. In dit proefschrift onderzocht ik 1) welke behoeftes aan sociale ondersteuning patiënten proberen te vervullen door verschillende informatiebronnen met elkaar te combineren (in het Engels *convergence* genoemd), 2) hoe de behoeftes aan sociale ondersteuning het internetgebruik voor gezondheidsinformatie beïnvloeden, en 3) de effecten van het combineren van deze verschillende informatiebronnen op tevredenheid over het consult, herinnering van medische informatie, en therapietrouw. Om deze vragen te beantwoorden werden er drie empirische onderzoeken uitgevoerd die in dit proefschrift zijn gebundeld.

A

Online Content en Behoeftes van Patiënten

In Hoofdstuk 2 onderzocht ik hoe de inhoud van verschillende platformen op een gezondheidswebsite (*kanker.nl*) gekoppeld kunnen worden aan de behoeftes aan sociale ondersteuning van patiënten. Tot dan toe werd internetgebruik als een containerbegrip gebruikt. In deze conceptualisatie werd genegeerd dat het internet vele verschillende platformen bevat, zoals blogs, forums, en online medische bibliotheken. In Hoofdstuk 2 gebruikte ik een hybride methode, bestaande uit kwalitatief onderzoek en een ongerichte computergestuurde inhoudsanalyse (*unsupervised machine learning*), om per platform in kaart te brengen welke behoeftes aan sociale ondersteuning op het platform terug te vinden zijn. Ik heb een onderscheid gemaakt in die platformen die peer-gegenereerde inhoud bevatten en die expert-gegenereerde inhoud bevatten. Peer-gegenereerde inhoud is geschreven door een ervaringsdeskundige zoals een patiënt terwijl expert-gegenereerde inhoud is geschreven door een professional met een medische achtergrond. Om de inhoudsanalyse theoretisch te onderbouwen werd gestart met een literatuurstudie om zo een overzicht te krijgen van verschillende behoeftes aan sociale ondersteuning. Deze behoeftes zijn gebaseerd op literatuur waarbij voornamelijk offline bronnen werden bekeken, de vraag is dan ook of online dezelfde behoeftes worden vervuld? Deze literatuurstudie heeft geleid tot het theoretische model: *Het model van behoeftes aan sociale ondersteuning voor patiënten*. Het model bevat de latente theoretische concepten zoals de cognitieve en affectieve behoeftes van patiënten en werkt via een aantal stappen deze theoretische concepten uit tot direct waarneembare onderwerpen die we terug kunnen

vinden via een computergestuurde inhoudsanalyse. De volgende stap was het koppelen van de online inhoud op de verschillende platformen met de verschillende behoeftes aan sociale ondersteuning uit het model. Een topic model op de inhoud ($N_{posts} = 52.990$) van twee peer-gegenereerde platforms (blogs en forums) en twee expert-gegenereerde platforms (een medische bibliotheek en vraag en antwoord paginas) leverde 25 onderwerpen op. Deze onderwerpen werden vervolgens gekoppeld aan de verschillende behoeftes aan sociale ondersteuning die voortkwamen uit de literatuurstudie. De inhoud online was grotendeels in lijn met het *model van behoeftes aan sociale ondersteuning voor patiënten* welke gebaseerd was op behoeftes die in voornamelijk offline bronnen werden vervuld. Er werd één categorie toegevoegd aan het model, namelijk het *delen van status*. In deze categorie delen patiënten hoe zij zich op het moment van schrijven voelen, hun ervaringen uit het verleden, of hoe het gaat met een naaste of geliefde die gediagnosticeerd is met kanker. Er werden daarnaast zowel verschillen tussen, als binnen peer- en expert-gegenereerde platformen gevonden. Inhoud afkomstig van peer-gegenereerde platformen was meer gericht op affectieve onderwerpen (affectieve support) terwijl op expert-gegenereerde platformen meer cognitieve onderwerpen (cognitieve support) werden besproken. Ook tussen de verschillende peer-gegenereerde platformen werden verschillen gevonden. Op blogs schrijven patiënten voornamelijk hoe het op dat moment gaat, terwijl op forums patiënten hun ervaringen uit het verleden delen.

In dit hoofdstuk laat ik zien hoe multidimensionaal online gezondheidsinformatie is en ontwikkel ik een concrete onderzoeksmethode om onderscheid te maken tussen peer- en expert-gegenereerde gezondheidsinformatie. Daarnaast bouw ik verder op het idee dat het internet verschillende platformen bevat die elk verschillende functies hebben; door aan te tonen dat de inhoud op deze platformen verschillen en gelinkt kunnen worden aan de verschillende behoeftes aan sociale ondersteuning voor patiënten. Het algoritme dat werd ontwikkeld in deze studie kan worden gebruikt om online inhoud beter te classificeren en te doorzoeken. Op deze manier kan het patiënten helpen om op websites gemakkelijker en passendere inhoud te vinden op basis van hun specifieke behoeftes aan sociale ondersteuning.

Intra- en Inter-medium Convergence

In Hoofdstuk 3 borduurde ik verder op het fenomeen dat patiënten verschillende informatiebronnen met elkaar combineren met als doel om de behoeftes aan sociale ondersteuning te vervullen (dit wordt ook wel *convergence* genoemd). In dit hoofdstuk onderzocht ik specifiek hoe vaak de combinatie van verschillende informatiebronnen te zien was op een forum van kanker.nl, hoe het gebruik van deze verschillende informatiebronnen invloed had op wat gebruikers op het forum schrijven, de motieven die gebruikers hadden om iets te schrijven op een forum, en welke behoeftes patiënten probeerde te vervullen door op een forum een gesprek te starten. Net als in Hoofdstuk

2 werd er gebruik gemaakt van een hybride methode, namelijk een handmatige inhoudsanalyse gevolgd door een gerichte computergestuurde inhoudsanalyse (*supervised machine learning*). Met behulp van deze methode kreeg ik meer inzicht in hoe vaak patiënten verschillende informatiebronnen gebruiken waarbij ik onderscheid maakte tussen de combinatie van massamediale en interpersoonlijke informatie bronnen (*intermedium convergence*) en het gebruik van twee massamediale informatiebronnen (*intramedium convergence*). Hierbij heb ik enkel de eerste berichten in een forum geanalyseerd. In totaal werden 1.708 openingsberichten geanalyseerd. In bijna een derde van alle openingsberichten werden aanwijzingen voor het gebruik van verschillende informatiebronnen gevonden. De berichten waarin gerefereerd werd naar het gebruik van massamediale bronnen werden vaker gebruikt om de online gemeenschap te versterken, om persoonlijke ervaringen te delen, of om naar informatie te vragen dan openingsberichten zonder deze referenties. Deze berichten bevatten echter minder persoonlijke informatie van de schrijver dan berichten zonder referenties naar andere informatiebronnen. Vergeleken met openingsberichten zonder referenties naar het gebruik van verschillende informatiebronnen, zag ik dat schrijvers die naar interpersoonlijke informatie bronnen verwezen, meer persoonlijke details in hun post verwerkten en mede forumgebruikers vaker vroegen naar hun ervaringen. Wanneer we kijken naar verschillen binnen berichten met verwijzingen naar andere informatiebronnen, vond ik dat openingsberichten met verwijzingen naar interpersoonlijke informatie bronnen minder vaak het gebrek aan informatie als motief om online te gaan benadrukten. Daarnaast bevatten deze openingsberichten meer informatie over de ziekte van de schrijver en werd actiever naar ervaringen van mede forumgebruikers gevraagd, vergeleken met openingsberichten waarin gerefereerd werd naar massamediale informatiebronnen.

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In Hoofdstuk 3 bouw ik voort op het fenomeen dat patiënten verschillende informatiebronnen met elkaar combineren (convergence) met als doel om de behoeftes aan sociale ondersteuning te vervullen en breid ik de definitie van dit fenomeen uit. In het verleden werd convergence tweeledig gedefinieerd. Ten eerste, type 1 bestond uit een combinatie van online gezondheidsinformatie en het daaropvolgende interpersoonlijke contact met een arts (alleen in deze volgorde). Type 2 bestond uit gemedieerde interpersoonlijke communicatie online zoals op forums. Het probleem hiermee is dat officieel het raadplegen van een arts en vervolgens online gaan om aanvullende behoeftes aan sociale ondersteuning te vervullen niet onder convergence zou vallen. Of als je deze combinatie wel wilde onderbrengen in een van de twee types dan zou je het alleen labelen als type 2 convergence, interpersoonlijke communicatie online. Hiermee vervalt echter de eerste bron, en mogelijk de reden om online te gaan, de communicatie met de arts. Door de volgorde niet meer mee te nemen in de definitie, maar te kijken naar wat voor soorten bronnen worden gecombineerd (inter- of intramedium convergence) blijft belangrijke informatie behouden terwijl er ook toegewerkt wordt naar een uniforme

definitie. Daarnaast pas ik, naar mijn weten voor het eerst, het fenomeen toe op forumdata en laat ik zien hoe patiënten verschillende motieven hebben om informatiebronnen te combineren. Hierbij zet ik de eerste stap om convergence verder te brengen dan alleen een theoretisch fenomeen en laat ik tevens zien hoe convergence samenhangt met de motieven om online te gaan en welke behoeftes aan sociale ondersteuning patiënten proberen te bevredigen door verschillende vormen van convergence in te zetten.

Het Bespreken van Online Gezondheidsinformatie en Patiëntuitkomsten

In Hoofdstuk 4 maakte ik gebruik van een combinatie van data afkomstig uit vragenlijsten en video en audio opnames van consulten tussen verpleegkundige en patiënt ($N = 165$). In de vragenlijst werd onder andere internetgebruik bevraagd en gesprekken werden specifiek gecodeerd op verwijzingen naar het internetgebruik van de patiënt. Door het combineren van deze data werd meer inzicht verkregen in de effecten van het bespreken van online gezondheidsinformatie tijdens het consult op patiëntuitkomsten. In Hoofdstuk 4 wilde ik inzicht krijgen in of patiënten überhaupt hun internetgebruik bespreken tijdens een consult en was ik geïnteresseerd in de effecten van het bespreken van internetgebruik op de mate van tevredenheid, het herinneren van de informatie, en therapietrouw. Van alle geïncludeerde patiënten zocht ongeveer 50 procent voorafgaand aan het consult online naar gezondheidsinformatie. Van deze internet-geïnformeerde patiënten besprak ongeveer de helft (46.81%) deze informatie met de verpleegkundige gedurende het consult. Bij het bestuderen van de effecten van het bespreken van online gezondheidsinformatie vond ik dat patiënten die hun online gezondheidsinformatie bespraken een hogere mate van tevredenheid over het gesprek met hun verpleegkundigen hadden. Patiënten die meer tevreden waren, onthielden de informatie beter als zij hun online zoekgedrag bespraken. Er werd geen relatie gevonden tussen het bespreken van online gezondheidsinformatie en therapietrouw. Gebaseerd op deze bevindingen werd het *model van gezondheidsinformatie triangulatie* voorgesteld. Dit model kan richting geven aan vervolgonderzoek naar de effecten van online gezondheidsinformatie op arts-patiënt communicatie en patiëntuitkomsten. Door het combineren van data afkomstig uit een vragenlijst en opnames van consulten kon ik laten zien dat het gebruik van de twee meest gebruikte informatiebronnen (het internet en de zorgverlener; *intermedium convergence*) een positief effect heeft op twee belangrijke patiëntuitkomsten: de mate van tevredenheid en het onthouden van de informatie. Hierbij onderstreep ik het belang van het bespreken van de informatie die op het internet gevonden is met de zorgverlener.

Afsluitende Noot

De grootste toevoeging van dit proefschrift is dat het een overzicht geeft van de verschillende online platformen die patiënten met kanker kunnen gebruiken, de informatie op deze platformen, en hoe deze inhoud gerelateerd is aan de behoeftes aan sociale ondersteuning. Als laatst laat ik zien hoe patiënten actief gebruik maken

van een combinatie van massamediale en interpersoonlijke informatie bronnen om hun behoeftes aan sociale ondersteuning te vervullen, en hoe convergence de potentie heeft om patiëntuitkomsten positief te beïnvloeden. Dit alles leidt tot twee modellen waarin samengevat wordt hoe behoeftes aan sociale ondersteuning van patiënten (mede) online vervuld kunnen worden en wat de effecten van het gebruik van deze twee informatiebronnen op patiëntuitkomsten zijn.

Het zoeken naar, en gebruiken van, online gezondheidsinformatie gebeurt niet in een vacuüm. Integendeel, het wordt beïnvloed door het gebruik van eerdere bronnen en het beïnvloedt het gebruik van eventueel volgende bronnen. Deze wisselwerking van verschillende informatiebronnen verdient meer aandacht, zowel in de praktijk als in de wetenschap.

Hoewel sommige patiënten de vaardigheid hebben om alle mogelijk platformen te gebruiken, zijn er patiëntengroepen die deze vaardigheden missen en daardoor problemen ondervinden met het vinden van de juiste informatie online. Met name deze groep patiënten verdient het om beter begeleid te worden in het proces van het vervullen van de verschillende behoeftes aan sociale ondersteuning. Betere integratie van online gezondheidsinformatie in consulten en een online omgeving die beter aansluit bij de leefwereld van patiënten, zoals het inrichten van de online omgeving op basis van behoeftes aan sociale ondersteuning, kan de eerste stap zijn naar een betere vervulling van hun behoeftes.

Dankwoord

Ik schrijf mijn dankwoord, de eerste versie daarvan, midden in het afrondingsproces van mijn proefschrift. Maar ik begin op tijd, omdat ik weet dat mijn woorden anders tekort zullen schieten in de liefde, bewondering en appreciatie die ik voel voor de mensen die ik wil bedanken. Alleen herschrijven en nogmaals herschrijven kan dat gat zo klein mogelijk maken. Terugkijkend op mijn promotieonderzoek, is de totstandkoming ervan niet vanzelf gegaan. Het proces omvat periodes van hoogte- en dieptepunten, vertrouwen en twijfel, en vooruitgang en lethargie. Een periode waarin ik heb geleerd dat hoe breed de blokkades ook zijn, wat overblijft altijd breder is. Net als een berg, gezien vanaf een afstand, ziet het proefschrift er soms ongenaakbaar en massief uit, maar wanneer je dichterbij komt, wordt wat je eerst als één geheel aanzag, geleidelijk opgedeeld in afzonderlijke etappes. Wat in het begin extreem steil leek, krijgt, naarmate je bezig bent en dichterbij komt, weer een zachte glooiing. En dus ligt er straks een proefschrift, een product waarvoor ik veel mensen dankbaar ben, mensen die mij hebben geholpen dichterbij de berg te komen en mij in beweging hielden. Mensen die ervoor hebben gezorgd dat de weg die ik moest bewandelen duidelijk werd.

Mijn (co)promotoren: Annemiek, Julia en Rens, ik had mij geen beter promotieteam kunnen wensen.

Annemiek, jouw ontwapenende openheid en doorzettingsvermogen maakte jou tot niet alleen een inspirerende (co)promotor, maar ook iemand waarmee ik graag ging zitten met een kop koffie en zowel werk als privé mee besprak. Ik ben blij dat ik negen jaar geleden besloot om te starten als jouw student assistent. Jouw passie voor onderzoek en je eigen manier van het uitvoeren van dat onderzoek hebben mij altijd aangesproken. Het is waar, als je eenmaal iets wilt, dan rust je ook niet tot het gedaan is! Je doorzettingsvermogen en voortdurende betrokkenheid bij het project, zelfs op momenten waarop iedereen had kunnen begrijpen als je je op jezelf had gefocust, zijn iets wat ik altijd zal blijven waarderen. Bedankt voor al je steun en inhoudelijke feedback gedurende al die jaren. Gelukkig zit onze samenwerking er nog niet op!

Julia, wat ben ik blij dat ik bijna acht jaar geleden begon als “jouw” assistent. Ik herinner mij nog één van de eerste klusjes, het verplaatsen van je boekenkast, niet wetende dat ik acht jaar later mede dankzij jouw begeleiding nu promoveer. Als PhD bewonder ik hoe persoonlijk je altijd betrokken bent geweest bij mij en het project, ondanks dat je ontelbaar veel andere taken en verantwoordelijkheden hebt. Bedankt voor alle inhoudelijk begeleiding maar ook voor alle persoonlijke betrokkenheid. Wie belt nu elke avond met

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Rens, wat ben ik blij dat jij onderdeel uitmaakte van het promotieteam. Jouw kalmte en ervaring hebben mij meer dan eens gerustgesteld. De korte gesprekken aan het begin van de week over het hardlopen tijdens het weekend, gaven mij de nodige rust en een zekere relativering van het werk. Ik waardeer dat je, ondanks je overvolle agenda, altijd beschikbaar was om te sparren over de methode, het schrijfproces, en het combineren van werk en privé. Wat ik nog steeds niet begrijp is dat je zowel kunt mailen als luisteren tijdens een meeting, maar hoe doeltreffend je altijd antwoord hebt gegeven op vragen maakt dat ik geen seconde twijfel dat jij beide tegelijk kunt!

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Beste Hans, jij bent letterlijk en figuurlijk mijn eerste kennismaking met de wetenschap in het algemeen en communicatiewetenschap in het bijzonder. Je gaf het eerste college ICW. In de jaren die erop volgden hebben we elkaar niet veel gesproken, maar de gesprekken die we voerden waren open en eerlijk en je hebt mij op meerdere momenten gerust weten te stellen en laten zien in welke ogenschijnlijke kalmte je te werk kunt gaan. Bedankt!

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Eny, we hebben elkaar niet vaak gezien of gesproken, maar de literatuur omtrent het welzijn van patiënten en online discussiegroepen hebben mij vanaf het begin van mijn proefschrift geïnspireerd. Ik kijk daarom uit naar jouw vragen en je oordeel over het proefschrift.

Marij, wij hebben elkaar in het laatste deel van mijn promotietraject leren kennen. Door omstandigheden in mijn leven is dat hoofdstuk niet in het proefschrift opgenomen. Maar in die korte tijd ben ik verrast door de snelheid en grondigheid van jouw feedback. Het resultaat is dat er nu een mooie studie klaarligt om uitgevoerd te worden. Iets waar ik nu weer alle aandacht voor heb nu het proefschrift is afgerond!

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Dear Rick Street, thank you for all the time and effort you put into my research visit at Texas A&M. I still think fondly about my time there, and I can still visualize my ride from the air B&B to the campus (crossing Wellborn Road by bike is always a challenge). Your knowledge and experience in research among patients and into patient-provider communication have helped me to shape a study that unfortunately did not make this dissertation. However, that only gives me a reason to continue my research after this dissertation and I look forward to sharing the progress of that study with you.

Mijn paranimfen, wat een luxe om jullie alle drie straks naast mij te hebben staan.

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uur op een balkon in de sneeuw. En ondanks dat je altijd door de wedstrijd heen praat, kijk ik uit naar de komende jaren!

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Author Contributions

Chapter 2

Title: Different Platforms for Different Patients' Needs: Automatic Content Analysis of Different Online Health Information Platforms

Researchers involved: Remco Sanders (RS), Annemiek J. Linn (AL), Theo B. Araujo (TA), Rens Vliegthart (RV), Mies C. van Eenbergen (MvE), Julia C.M. van Weert (JvW)

	Limited Contribution	Substantial Contribution
Conceptualization (Main idea, Theory)		RS, AL, RV, JvW
Methodology (Design, Operationalization)		RS, AL, TA, RV, JvW,
Data Collection		MvE
(Statistical) Analysis		RS, TA
Writing (original draft preparation)		RS, AL, RV, JvW
Writing (review and editing)	MvE	RS, AL, RV, JvW, TA
Visualization		RS, AL, RV, JvW
Funding acquisition	-	-

Chapter 3

Title: Patients' Convergence of Mass and Interpersonal Communication on an Online Forum: Hybrid Methods Analysis

Researchers involved: Remco Sanders (RS), Annemiek J. Linn (AL), Theo B. Araujo (TA), Rens Vliegthart (RV), Mies C. van Eenbergen (MvE), Julia C.M. van Weert (JvW)

	Limited Contribution	Substantial Contribution
Conceptualization (Main idea, Theory)		RS, AL, RV, JvW
Methodology (Design, Operationalization)		RS, AL, TA, RV, JvW,
Data Collection		MvE
(Statistical) Analysis		RS, TA
Writing (original draft preparation)		RS, AL, RV, JvW
Writing (review and editing)	MvE	RS, AL, RV, JvW, TA
Visualization		RS, AL, RV, JvW
Funding acquisition	-	-

Chapter 4

Title: A Mixed Method Study Investigating the Impact of Talking about Patients' Internet Use on Patient-Reported Outcomes.

Researchers involved: Remco Sanders (RS), Annemiek J. Linn (AL), Julia C.M. van Weert (JvW)

	Limited Contribution	Substantial Contribution
Conceptualization (Main idea, Theory)		RS, AL
Methodology (Design, Operationalization)		RS, AL
Data Collection		RS, AL
(Statistical) Analysis		RS
Writing (original draft preparation)		RS, AL
Writing (review and editing)	JvW	RS, AL
Visualization		RS, AL
Funding acquisition	-	-
