

This document is the Accepted Manuscript version of a Published Work that appeared in final form in:

Laukka, E., Rantakokko, P., & Suhonen, M. (2017). Consumer-led health-related online sources and their impact on consumers: An integrative review of the literature. *Health Informatics Journal*. <https://doi.org/10.1177/1460458217704254>

Consumer-led health-related online sources and their impact on consumers: an integrative review of the literature

The aim of the review was to describe consumer-led health-related online sources and their impact on consumers. The review was carried out as an integrative literature review. Quantization and a qualitative content analysis were used as an analysis method. The most common method used by the included studies was qualitative content analysis. This review identified the consumer-led health-related online sources used between 2009 and 2016 as health-related online communities, health-related social networking sites and health-related rating websites. These sources had an impact on peer support, empowerment, health literacy, physical, mental and emotional wellbeing, illness management and relationships between healthcare organisations and consumers. The knowledge of the existence of the health-related online sources provides healthcare organisations with an opportunity to listen to their consumers' "voice". The sources make healthcare consumers more competent actors in relation to healthcare, and the knowledge of them is a valuable resource for healthcare organisations. Additionally, these health-related online sources might create an opportunity to reduce the need for drifting among the healthcare services. Healthcare policymakers and organisations could benefit from having a strategy of increasing their health-related online sources.

Keywords: internet, online source, healthcare, consumer, integrative review

Introduction

The internet has become the major resource of information relating to health (Johnsson & Lowe 2011, Morgan et al. 2014) and its use by healthcare consumers is expected to increase (Wanberg 2009). The internet, with its ubiquitous nature and potential anonymity (Ziebland & Wyke 2012), has fascinated millions of healthcare consumers who access it every day to find health-related information (Koch-Weser et al. 2012, O'Neill 2014). The channels that the healthcare consumers use, either for obtaining or sharing health-related information, are, in this review, called health-related online sources. In this review, the sources are assumed to be consumer-led, which here means that they are not offered by healthcare organisations. For the internet user searching for health-related information, this review uses the term consumer, which has replaced the term patient (Lober and Flowers 2011). Health policymakers have begun to recognise the potential of the internet as a source of consumers' experiences (Ziebland & Wyke 2012) and, in the United Kingdom's NHS Future Forum Report on Information (2012), have actually talked about "a new culture of transparency and public voice being fuelled by the digital revolution".

Studies have revealed the need for combining healthcare and the internet in order to produce better services (Josefsson 2005, Sittig et al. 2001, Hanson et al. 2014). Previous

studies have addressed this idea from four key viewpoints. The first observed health-related online sources through the lenses of marketing and was, therefore, interested in how the marketing of health services can benefit from online sources and consumers' experiences (for example, Rooney 2009, Terlutter et al. 2014). The second viewpoint was related to health science, which, in most cases, focused on how successful interventions, tools and guidelines using the internet (for example, Camerini & Schulz 2012, Hanson et al. 2014) were. The third viewpoint covered misleading and unverifiable information (for example, Collins & Lewins 2013, Cole et al. 2016). The fourth viewpoint was technological, which primarily examined the development of health-related online sources for the purposes of healthcare (for example, Bhandari & Snowdon 2012). Despite the increased research interest in the use of the internet in the healthcare context, research into health-related online sources seems to be limited: quite little is known about their impact (Ziebland & Wyke 2012, O'Neill 2014).

The aim of this study is to describe the consumer-led health-related online sources and their impact on consumers. The research questions are:

1. How have health-related online sources been studied in the past?
2. What kind of consumer-led health-related online sources have been accessed between 2009 and 2016?

3. What kinds of impact of health-related online sources have been explored by previous studies?

The use of health-related online sources, drifting among them and the implications

Internet usage differs between countries and across continents. For example, mainstream culture might create certain attitudes towards internet use, thereby reducing it among a certain part of the population. Also, access to the internet varies and is most often bound to the development of the country (Akhu-Zaheay & Dickerson 2009). Users of the internet, compared to non-users, tend to be more educated and have better earnings; their mean age is 45.8 years (Andreasen et al. 2007, Diaz et al. 2002, Houston & Alison 2002). Several studies have reported health-related internet usage to be more common among women (Andreasen et al. 2007, Diaz et al. 2002). The Norwegian study carried out by Wanberg et al. (2009) found no significant differences between genders' health-related internet use. This review uses characteristics of internet users that could be applied to the Scandinavian population, where internet use is very high. The Scandinavian countries all have similar health-related internet usage. According to Norwegian, Swedish and Finnish studies, nearly 70% of Scandinavian people have used the internet to find illness, nutrient or other health-related information (Wanberg 2009, .se 2012, Statistics Finland 2009). Using the internet for these purposes is, in this review, understood to mean using health-related online sources; the channels offering

such information are referred to as health-related online sources. When healthcare consumers offer these sources, these sources are, in this review, understood to be consumer-led.

The relationship between healthcare consumers and the internet is to be expected, since learning more about a disease and interacting with others in a similar situation are the major coping strategies used by the consumer (Josefsson 2005). Ye (2014) found out that people without a family history of cancer were half as likely to participate in online health activities. Healthcare consumers as users of the internet play different roles: patients, caregivers and family members coping with the illnesses of others in the household (Johnson & Lowe 2011). It has been claimed that online consumers do not want to be treated as stereotypical patients with a specific condition (Easterling 2001). Thus, one of the main ways in which healthcare consumers are asserting their individuality is through the internet and online sources. The internet offers a way to question healthcare providers and professionals (Ziebland et al. 2004), search for information relating to second opinions, complementary or alternative medicines, and learn about specific diagnoses (Diaz et al. 2002). The internet increases the consumer's ability to influence their healthcare (Josefsson 2005). The information taken from the internet seems to be highly appreciated (Diaz et al. 2002, Taylor 2012), since as much as 60% of consumers looking for information on the internet considered the information

found to be as good as, or better than, the information received from a doctor (Diaz et al. 2002).

Healthcare consumers' feedback is posted on the internet for the whole world to see (Thielst 2011), and thus it offers scientists, society and end-users the chance to learn what their consumers have to say. In addition, in most Scandinavian countries, healthcare is in crisis caused by an aging population and failing economies (Newbold & Hyrkäs 2010). The internet has been seen as society's chance to secure good patient-centred care, since the major benefit of the internet is its ubiquitous nature. Thus, it can be easily applied in healthcare environments to solve modern challenges (Thielst 2011). Ultimately, the evaluation and usage of health-related online sources is a job for end-users, for whom these online sources can provide an opportunity to produce services that are of high quality, driven by experience-based knowledge, to increase the safety of consumers and help healthcare administrations to find innovative ways (Laing et al. 2011) of using such health-related online sources for development.

Methods and materials

The review was carried out as an integrative literature review with a qualitative content analysis being used as an analysis method. The integrative review was chosen for this review since it is especially useful and applicable in areas where there is only a little

pre-existing knowledge and where the issues are complex and require more detailed exploration. Literature searches were conducted in accordance with guidelines relating to literature reviews (Joanna Briggs Institute 2011).

The data were collected using well-known healthcare and administration databases: CINAHL, Business Source Complete (EBSCO), ABI/INFORM complete and PsycINFO (Table1). To make sure that information retrieval was relevant, a librarian was consulted to determine the appropriate search strategy for this area of research. The information retrieval was carried out by using relevant words for the phenomenon, including their combinations and synonyms, and by finally undertaking test searches in the selected databases. The search for some terms was limited to the title of the article in order to deal with the volume of results. The inclusion and exclusion criteria for the studies were determined at the beginning of the process.

KEYWORDS	DATABASE	RESULTS
ti(internet OR online OR web* OR virtual* OR “network* site”)	CINAHL	446
AND (consumer* OR patient* OR user*) AND ti(health* OR “health care” OR “health service**”)	EBSCO	110
	ABI/INFORM Complete	95
	PsycINFO	251 (not included after 2013)
Manual search	Journal of Medical Internet research (including the article from the Medicine 2.0)	49
	Telemedicine and e-Health	1
	Patient Education and Counseling	2
Total		954
Total after duplicates removed		764
Inclusion and exclusion criteria	(1) Peer reviewed original scientific articles; (2) published between 2009 and 2016 in the electronic databases; (3) either in English, Swedish or Finnish; (4) full text available through the Library of the University of Oulu; (5) focused primarily on consumer-led health-related online sources; (6) were found to be of good quality according to a critical appraisal tool and (7) were undertaken in a context of developed countries having similar internet usage to Scandinavia. The studies (1) exploring the	

population whose ability to use internet due to illness differed
from the mainstream were excluded.

Table 1: Search strategy

In this review, a manual search was carried out using the journals that appeared to include good and relevant studies after the database search. The journals scrutinized were: The Journal of Medical Internet Research, Telemedicine and e-Health, and Patient Education and Counseling. While researching The Journal of Medical Internet Research using its official webpages, one good article was found from a journal called Medicine 2.0, and it was included. The previous year range of 2009 to 2016 was also valid for this search. In total, the number of articles found was 954, which reduced to 764 after duplicates were removed either using Refworks.

Following the information retrieval, the studies' titles and abstracts were screened by the primary author. If no abstract existed, or a decision on inclusion could not be made from the abstract alone, the whole text was analysed. In the second screening, the studies' complete texts were screened and, prior to inclusion, their quality was appraised by two independent researchers using their own criteria for quantitative, qualitative and mixed-method studies. Suitable critical appraisal tools were found from the list by the Sansom Institute (2013) and modified forms of the following tools were applied: McMaster Critical Review Form (for quantitative studies), Critical Appraisal Skills Programme (CASP) screening tool for qualitative studies and Evaluation Tool for Mixed Methods Studies. Since there is no specific threshold to determine whether a study is of sufficient quality (Whittemore & Knafel 2005), the studies were included if

they met a minimum of 50% of the addressed criteria or were otherwise felt to be of sufficient quality. If there were any disagreements over the quality, they were resolved through discussions and further reading of the full text until a consensus was reached.

Finally, 26 studies were chosen. The studies were analysed by using qualitative content analysis in which the aim is to understand the contents of the text and search for the essential themes in the studies (Denzin & Lincoln 2011). In addition, quantisation was used while addressing the first research question. After reading and understanding the content of the studies, the following topics were produced for addressing the second research question: health-related online communities, health-related rating web pages and health-related social networking sites (Table 2). The following impacts were found that addressed the third research question: peer support, empowerment, health literacy, physical, mental and emotional wellbeing, illness management and relationships between healthcare organisations and consumers.

The research methods used and the branches of sciences covered in studies exploring health-related online sources and their impact on consumers

Of the 26 studies selected for this review (Table 2), thirteen were carried out using qualitative methods, seven using quantitative methods and six using a mixture of both. The sources of the information were most often healthcare consumers but caregivers were also included in a few studies. By caregiver, studies meant either healthcare professionals or relatives of a patient suffering from a specific illness. Research data were most often collected either through observation or using surveys but a few studies used interviews, and one study was carried out as secondary analysis. The most popular method was observation, which was most often used in the context of health-related online sources. Some studies used more than one data collection method with online surveys often being used. The studies were carried out in the following countries: United States, United Kingdom, Netherlands, Canada, Norway, Japan, Australia and Spain. Some of the studies covered more than one country, but the most commonly researched countries were United States, United Kingdom and Netherlands. Also, the Spanish study and the other Spanish-Norwegian study examined English-speaking sources.

Most of the data were processed using different types of analytical methods, which produced descriptive information. The qualitative studies were most often analysed

using content analysis, but also discourse analysis, text analysis, thematic analysis, social network analysis and video analysis were carried out. The quantitative methods used in analysing data were statistical analysis methods, of which the most popular were Chi Square, Kruskal Wallis, Student's T-test, correlations, logistic regression and ANOVAs.

The health-related online sources were explored from the viewpoint of health science, medicine, psychology, economics and informatics. One of the studies clearly combined two branches of science, whilst several other studies were less clear on their combinations of scientific fields. The combination of sciences used most often was nursing or medicine combined with informatics.

The Author(s) and the Journal	The Aim of the Study	<i>1st Research Question:</i> Data and Methods	Country	Conclusions	<i>2nd research question:</i> Online sources	<i>3rd research question:</i> Impact
Donelle & Hoffmann-Goetz (2009) Informatics for Health and Social Care	To examine and compare cancer-related conversations in online forums hosted by Canadian and American associations for retired people.	There were 125/1817 (6.8%) Canadian cancer-based discussions and 70/892 (7.8%) American-based cancer based discussions. A content analysis was carried out.	Canada US	Online discussion forum associations may serve as an important channel for information about cancer prevention and screening, treatment and care support, and healthcare advice for seniors.	Health-related online communities	Health literacy
Dolce (2009) Oncology Nursing Forum	To describe the experiences of cancer survivors with healthcare providers in the context of the internet as a source of health information.	Online cancer communities hosted by the Association of Cancer Online Resources. Purposive sample of 488 cancer survivors, with varying cancer types and survivorship stages, and caregivers. Secondary data analysis using Krippendorff	US	Through online health information and resources, concealed failures in healthcare relationships were revealed and cancer survivors and caregivers were empowered to influence and control care decisions.	Empowerment Health literacy Physical mental and emotional wellbeing Relationship between healthcare organisations and consumers	Empowerment Health literacy Physical mental and emotional wellbeing Relationship between healthcare organisations and consumers

		's thematic clustering technique of qualitative analysis.			
Bartlett & Coulson (2011)	To investigate perceptions of OSG (online support groups) users in both empowerment and communication with their health professionals .	246 participants across 33 chronic illness online support groups completed an online questionnaire. Data were explored using descriptive statistics, frequencies and correlations and analysed using both multiple and binary logistic regression.	UK	OSGs have the potential to produce empowerment outcomes for those who choose to use them. Furthermore, users report a positive reaction to information found online from their health professionals.	Empowerment
Batenburg & Das (2014a)	To predict that the effects of online support group participation would partly depend on patients' ability to cope with thoughts and emotions regarding the illness.	184 Dutch breast cancer patients filled out a questionnaire, of whom 163 were visiting an online peer-support community. Z scores and correlations.	Netherlands	Breast cancer patients' ability to cope with emotions and thoughts regarding the illness influence the relationship between online support group participation and psychological well-being.	Physical, mental and emotional wellbeing
Batenburg	To	A total of	Netherlands	Participating	Physical, mental

<p>& Das (2014b)</p> <p>Journal of Medical Internet Research</p>	<p>extend cross-sectional findings by tracking patients over an extended period of time to further assess individual emotional coping differences.</p>	<p>133 Dutch patients with breast cancer filled out a baseline questionnaire (T0) and a follow-up (T1, 6 months later). ANOVAs.</p>	<p>s</p>	<p>frequently online was especially helpful for patients who approach their emotions less actively; their emotional well-being increased over time.</p>	<p>and emotional wellbeing</p>
<p>Evans et al. (2012)</p> <p>Patient Education and Counseling</p>	<p>To examine the perceived value and types of social support that characterise the discussion of women who participate in postpartum depression online discussion groups.</p>	<p>A directed content analysis was used to examine 512 messages posted on a postpartum depression online support group over six month.</p>	<p>Canada</p>	<p>Online support groups provide women experiencing postpartum depression a safe place to connect with others and receive information, encouragement and hope.</p>	<p>Health literacy</p>
<p>Haukeland Fredriksen et al. (2016)</p> <p>Journal of Medical Internet Research</p>	<p>To understand how Web-based discussion forums influence maternal health literacy.</p>	<p>The sample included 11 Norwegian women who participated in open Web-based discussion forums when experiencing PGP in pregnancy. The data were collected</p>	<p>Norway</p>	<p>The popularity of Web-based discussion forums among pregnant women suggests that this group needs additional sources of information and support to complement traditional consultations</p>	<p>Peer support Empowerment Health literacy</p>

		using synchronous qualitative email interviews and were analysed using thematic analysis.		with health professionals.	
Gilbert et al. (2012)	To identify what key stakeholder groups most value about the Reality Check online community and to contribute the experiences from this long-running and self-sustaining online program to the growing field of peer support research.	42 patients participated in six focus groups and responded to seven questions raised by the facilitator. Thematic analysis.	Australia	The online community provides a wide range of support that is distinct from what can be received from clinical care. In addition, the online community increases its users' ability to manage their illness.	Peer support Illness management
Diabetes Spectrum					
Johnston et al. (2013)	To examine how participation in an online health community provides direct benefits in the form of information utility and social support and an indirect	A multi-method approach involving interviews with moderators of 18 online health communities and a field survey of 153 online health community	US	Online health community participation leads to direct benefits in the form of information utility and social support. That information utility also helps to shape perceptions of patient	Peer support Empowerment
Information Technology & People					

	influence on perceptions of patient empowerment.	participants.		empowerment among community participants.	
Huang et al. (2014)	To contrast community members' support behaviour and companionship activities in two large healthcare virtual support communities .	Combines both qualitative and quantitative methods. The target community is an online cancer support community. In total 2,009 messages and 317 members.	US	Findings suggest that increasing online avenues for, and encouragement for companionship activities in, any virtual support community could increase participation in support exchange, leading to improved health outcomes.	Peer-support Physical, mental and emotional wellbeing
Kordzadeh et al. (2014)	To examine user participation at the individual and group (thread) levels.	2,176 threads initiated by 130 users and 1,947 messages exchanged between these users and their peers. OLS regression and ANOVAs.	US	Results support short-term reciprocity, but refute the positive relationship associated with long-term reciprocity.	Peer support Health literacy
Loane & D'Alessandro (2014)	To explore the impact of online support groups on the doctor-patient relationship.	Combination of survey, interview and content analysis. 93 responses were received and the response	Australia	The traditional asymmetric relationship between patient and doctor is challenged by a new form of educated, empowered	Empowerment Health literacy

		rate was 4%.		health consumer who is able to work in partnership with medical service providers.	
McKechnie et al. (2014)	To examine the impact of a well-respected UK-based online support forum for carers of people with dementia.	8 participants were interviewed about their experiences of using the forum. Mixed method.	UK	Many of the reported experiences and benefits are unique to online peer support.	Peer support Health literacy
Journal of Medical Internet Research					Physical, mental and emotional wellbeing Illness management
Rupert et al. (2014)	To explore how individuals use OHC content in clinical discussions and how HCP's react to it.	In-person and virtual focus groups with patients/care givers who visited OHCs (n= 89). Thematic response analysis.	US	Individuals do not use OHCs to circumvent HCPs but instead to gather more in-depth information.	Illness management
Patient Education and Counseling					Relationship between healthcare organisations and consumers
Shoebbotham & Coulson (2016)	To examine the presence of therapeutic affordances as perceived by women who use endometriosis online support groups.	Sixty-nine women participated in a Web-based interview exploring online support group use. Responses were analysed using inductive thematic analysis.	UK, US	The SCENA (Self-presentation, Connection, Exploration, Narration, and Adaptation) model reveals a range of positive aspects that may benefit members, particularly in relation to reassurance and coping.	Peer support Empowerment Health literacy
Journal of Medical Internet Research					Physical, mental and emotional wellbeing Illness management
Willis	To examine	Online	US	Three themes	Peer support

(2016)	self-efficacy within the computer-mediated communication (CMC) of four online health communities	ethnography and discourse analysis (n=8,231).		follow: sharing disease experience, suffering from disease symptoms, and asking for help.	Empowerment Illness management
Zhao et al. (2015)	To seek to identify the motivators of activities in online health communities (OHC) and examine their specific and unique effects.	Six focal OHC members and their recent posts (n=81) and related threads (893 posts from 265 members). Netnographic study.	US	Social identity drives patients' value co-creation activities.	Peer-support
Journal of Service Management					
Wicks et al. (2010)	To describe the potential benefits of PatientsLike Me in terms of treatment decisions, symptom management, clinical management, and outcomes.	An online survey completed by 1323 participants from selected chronic disease groups. Various SPPS analyses.	US	The members of the community reported a range of benefits and felt these might be related to the extent of site use.	Empowerment Health literacy Physical, mental and emotional wellbeing Illness management Relationship between healthcare organisations and consumers
Epilepsy & Behaviour					
Wicks et al. (2012)	To gather feedback on the perceived benefits from use of our online service by	An online survey completed by 221 patients with epilepsy. Various SPPS	US	Perceived benefits included: finding another patient experiencing the same symptoms	Peer support Empowerment Illness management Relationship
Journal of Medical Internet Research					

	people with epilepsy.	analyses.		(59%), gaining a better understanding of seizures (58%) and learning more about symptoms or treatments (55%). The controlled sharing of health data may have the potential to improve disease self-management.	between healthcare organisations and consumers
Keeling et al. (2013) Journal of Service Marketing	To present data that demonstrate the construction of tacit knowledge within online health communities and how consumers exercise their “voice” within complex professional services.	Textual data were collected and analysed from the forum retrospectively from an 11-month period, entailing contributions from 252 participants. Content analysis using a simple “discourse analysis”.	UK	Forum participants negotiate their understanding in the context of their personal experience.	Empowerment
Setoyama et al. (2011) Journal of Medical Internet Research	To explore differences in peer support received by lurkers and posters in online breast cancer	An exploratory, descriptive, cross-sectional web-based survey of 253 members of	Japan	The participation in online communities – even as a lurker – may be beneficial to breast cancer patients’ mental	Peer support Physical, mental and emotional wellbeing

	communities . Also, the effects of such support on both groups' mental health were examined.	four Japanese online breast cancer communities . Various SPPS analyses.		health.		
Adams (2011) Social Science and Medicine	To examine comments made on the sites from the perspective of reflexivity in modern society. How are patients positioned by the websites and how do they position themselves when writing a review of received care?	A discourse analysis of four of the six sites under study, including patient reviews of institutions and professionals (n=450). Supplementary data from interviews with stakeholders related to the Dutch sites (n=15) is also used.	US, UK, Netherlands	The focus on reflexivity in healthcare means that not only must institutions be more transparent about their performance but also patients are expected to be more transparent about their choices as well.	Health-related rating websites	Empowerment Relationship between healthcare organisations and consumers
Black et al. (2009) Informatics in Primary care	To evaluate and describe online reviews of healthcare providers.	Analysed 16703 ratings of 6101 providers. Multivariate analysis and logistic regression analysis, and text analyses of narrative commentary (n=15952). Mixed method.	US	Online ratings were largely positive.		Illness management
Gómez-	To explore	Analysis of	Spain	The main	Health-	Peer support

Zuñica et al. (2012)	the motivations and challenges faced by the patients who share videos about their health and experiences on YouTube.	the videos created by 4 patients about their self-reported motivations and challenges they face as YouTube users.	Norway	reason for making videos was to bridge the gap between traditional health information about their diseases and everyday life. The first consequence of sharing their life on YouTube was a loss of privacy. However they also experienced the positive effects of exploring their feelings, being part of a large community of peers, and helping each other to deal with a chronic condition.	related social networking sites	Health literacy Physical, mental and emotional wellbeing Illness management
Takahashi et al. (2009)	To explore the potential benefits and dangers of an SNS (social networking service) for depression, based on a concurrent triangulation design of mixed methods strategy, including qualitative	A cross-sectional internet survey of 105 participants, which involved the collection of SNS log files and a questionnaire, was conducted in an SNS for people with self-reported depressive	Japan	An SNS for people with depressive tendencies provides various opportunities to obtain support that meets users' needs. It is recommended that participants do not use SNSs when they feel that the SNS is not user-		Peer support Empowerment Health literacy Physical, mental and emotional wellbeing

	content analysis and social network analysis.	tendencies. Mixed-method strategy.		selectable, when they receive egocentric comments, when friends have a negative assessment of the SNS, or when they have additional psychological issues.	
De la Torre-Diez et al. (2012)	To characterise the purpose and use of Facebook and Twitter groups concerning colorectal cancer, breast cancer and diabetes.	A content analysis of 216 breast cancer groups, 171 colorectal cancer groups and 527 diabetes groups on Facebook and Twitter.	Spain	Social networks are a useful tool for supporting patients suffering from diseases.	Health literacy

Table 2. Studies exploring health-related online sources and their impacts.

Consumer-led health-related online sources

Online communities (Figure 1) consist of large, geographically dispersed groups of healthcare consumers who may or may not know each other, but share a common interest (Johnston et al. 2013). Some of the online communities were distinctive groups only representing one illness, but some of them, such as PatientsLikeMe included several different forums for several different illnesses.

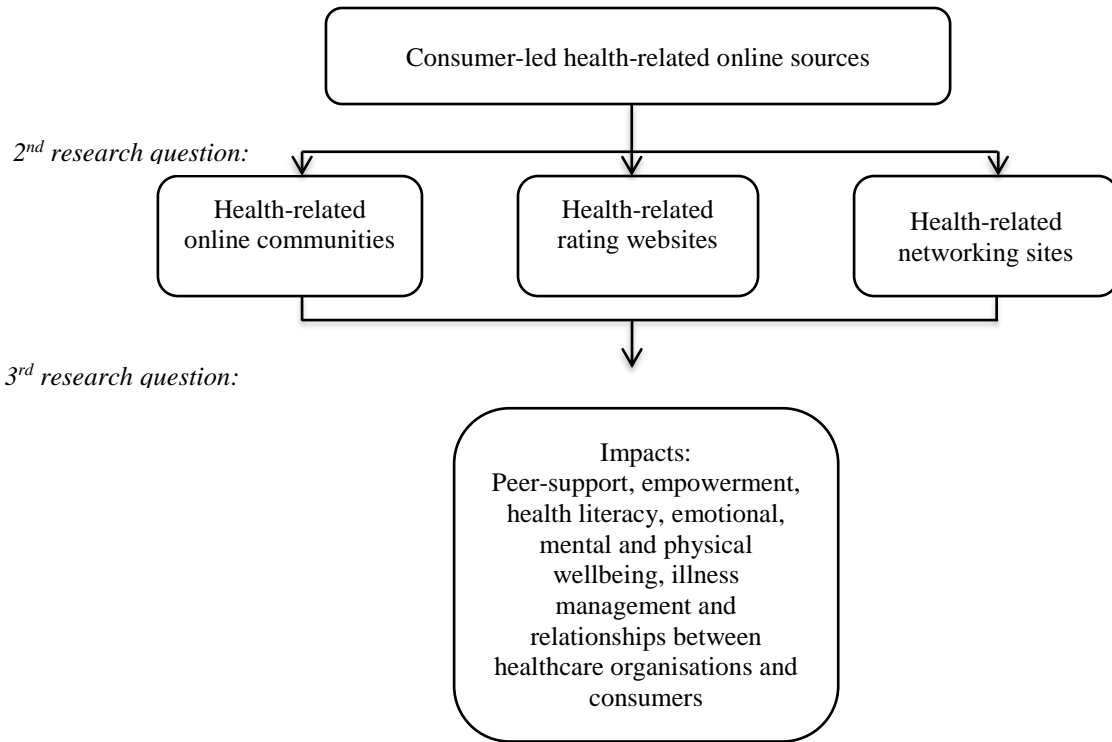


Figure 1. A synthesis figure for research questions 2 and 3.

Health-related online communities were usually used and developed by people with similar health experiences (Evans et al. 2012, Gilbert et al. 2012, Johnston et al. 2013, Setoyama et al. 2011). Their purpose was usually to increase knowledge among the healthcare consumers with particular illnesses (Wicks et al. 2010). The users of the online communities adopted different kinds of roles among the groups: they were either active posters or lurkers (Setoyama et al. 2011) and, in some cases, users of the groups became experts (Dolce 2009). Health-related online communities may contain social networking and rating possibilities (Loane & D'Alessandro 2014).

Social networking sites are internet-based Web 2.0 applications that allow online social networks to be created where individuals are able to share interests and activities (Takahashi et al. 2009). The included studies referenced three different social network sites that included content related to health: Facebook (De la Torre-Díez et al. 2012, Shoebbotham & Coulson 2016), Twitter (De la Torre-Díez et al. 2012), and Youtube (Gómez-Zúñiga et al. 2012). One of the studies did not specify the services used, but did reference MySpace. Health-related social networking sites gave similar types of support as health-related online communities (De la Torre-Díez et al. 2012, Gómez-Zúñiga et al. 2012) but they also included several disjunctive features. Social networking sites are different from the other online communities, since they allow the users to be made visible to their social networks (De la Torre-Díez et al. 2012).

Shoebbotham & Coulson (2016) noted that compared to health-related online communities, consumers expressed more concerns over privacy when using social networking sites. Social networking sites do not allow anonymous profiles unlike health related online communities. While communities are most often targeted at healthcare consumers with specific illnesses, health-related social networking sites also involve the mainstream population for purposes such as raising illness awareness (Gómez-Zúñiga et al. 2012), fundraising, advancing disease prevention, or fighting against the diseases (De la Torre-Díez et al. 2012).

Healthcare rating websites offer a consumer the chance to rate their medical providers (Black et al. 2009). They presented a different kind of viewpoint in comparison to the health-related online communities and social networking sites. On the rating websites, healthcare consumers did not share information about their illness but they evaluated the functionality of the healthcare organisations or physicians (Adams 2011, Black et al. 2009). On these sites, healthcare consumers reported their experiences of institutions, professionals, medication or treatments and could be asked to rate different aspects of the care, such as communication, hygiene or accessibility (Adams 2011).

The impact of the health-related online sources

All three of the consumer-led health-related online sources mentioned earlier aspire to increase the level of health-related information (Adams 2011, Gómez-Zúñiga et al. 2012, Wicks et al. 2012). Some of them evaluate illness-related information, whilst others may evaluate the information related to healthcare providers or professionals. They all have an impact on the person with the specific illness as well as society and healthcare in general, but they have different types of users and different ways of disseminating information (for example, Black et al. 2009, De la Torre-Díez et al. 2012). The primary impacts seen in studies exploring health-related online sources are: peer-support, empowerment, health literacy, physical, mental and emotional wellbeing, illness management and relationship between healthcare organisations and consumers.

In most of the cases, health-related online sources enabled peer support. Seeking a connection with others with the same medical condition is one coping strategy, with the resulting process being termed “peer support” (Gilbert et al. 2012). Healthcare consumers were able to find another person with similar symptoms through online sources. This made it possible to make new friends and share experiences, thus helping consumers to understand what it was like to have specific treatments for their condition (Shoebbotham & Coulson 2016, Takahashi et al. 2009, Wicks et al. 2012, Willis 2016,

Zhao et al. 2015). Sharing stories related to their illnesses made some consumers realize that other users of the online sources were in a worse situation than they were, which made some of them feel positive about their own situation (McKechnie et al. 2014). In some cases, online sources were not merely used for the purpose of peer-support but also for deeper companionship (Huang et al. 2014). Sometimes consumers took on the role of helper or adviser to others since they felt they had a lot of experience to share (for example Haukeland Fredriksen et al. (2016), Loane & D'Alessandro 2014, Shoebbotham & Coulson 2016). Several studies showed that health-related online sources created a strong feeling of belonging even becoming family-like, which again had positive impacts on emotional and physical wellbeing (for example Shoebbotham & Coulson 2016, Zhao et al. 2015). Zhao et al. (2015) noted that when consumers strongly identify with their health-related online source, they are more willing to co-create value with peers through sharing. Although peer support was most often seen as a positive impactor, Shoebbotham & Coulson (2016) noted that a small part of the consumers found arguments and preoccupation had negative impacts.

Empowerment is still poorly defined within literature (Van Uden-Kraan et al. 2008), but according to some views, an empowered healthcare consumer has been seen as a part of a more productive relationship with their healthcare professional (Wald 2007). According to this review, empowerment included different kinds of features, which

were usually combined with the fact that the consumer is better informed about the disease (Bartlett & Coulson 2011, Keeling et al. 2013, Loane & D'Alessandro 2014, Willis 2016). Being better informed enabled, for example, better knowledge of treatments, and the health-related online sources better prepared a consumer for consultations since they knew what questions to ask and felt more informed about the symptoms (Bartlett & Coulson 2011, Shoebbotham & Coulson 2016, Wicks et al. 2010). In addition, empowered consumers were able to question, persuade and even coerce healthcare professionals (Dolce 2011, Haukeland Fredriksen et al. 2016). Furthermore, they even took on roles similar to those of health educators and government agencies responsible for public health (Adams 2011).

According to Gómez-Zúñiga et al. (2012), health-related online sources were created because of a lack of information and, thus, one of their goals was to increase health literacy. Health literacy embodies the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that advance and maintain good health (Donelle & Hoffman-Goetz 2009). According to Kordzadeh et al. (2014), the primary goal of healthcare consumers is to seek health-related information, rather than socialising with peers. It was shown that health-related online sources made it possible to learn more about diagnoses, illnesses and treatments (for example, Takahashi et al. 2009, Wicks et al. 2010, Rupert et al.

2014). Healthcare consumers learned about the latest treatments and were able to access the best available research through health-related online sources (Dolce 2009). Many health care consumers commented that they were able to find information that had not been provided by medical professionals (Haukeland Fredriksen et al. 2016, Shoebatham & Coulson 2016). Some of the healthcare consumers turned to online sources since they did not know where else they could get information (McKehnie et al. 2014). These sources also developed the expertise of consumers, since, in some cases, users of the health-related online sources took the role of mentors or “patient experts” (Evans 2012, Gómez-Zuñiga et al. 2012, Loane & D’Alessandro 2014). The consumers said that even the healthcare professionals reported the growing level of expertise among consumers and noted that they were reaching higher levels of expertise than the professionals themselves (Dolce 2009). Health-related online sources were also a way of sharing health literacy among other people (De la Torre-Díez et al. 2012, Gómez-Zuñiga et al. 2012, Loane & D’Alessandro 2014).

Health-related online sources had an impact on physical, mental and emotional wellbeing (for example, Dolce 2009, Wicks et al. 2010, Huang et al. 2014, Rupert et al. 2014). Studies showed that being a member of a health-related online source may cause a reduction in behaviour that is harmful to their illness (Takahashi et al. 2009, Wicks et al. 2010). For example, membership of a particular health-related online support group

decreased HIV patients' risky behaviour and helped them decide to start taking antiretroviral drugs (Wicks et al. 2010). Online sources might also reduce the feeling of loneliness, help accept the condition, and through narration impact positively on mental wellbeing (McKechnie et al. 2014, Shoebbotham & Coulson 2016). According to Setoyama et al. (2011), who researched active posters and lurkers in Japanese online groups, a poster who received emotional support in online communities felt less anxious. Lurkers also experienced positive effects on their mental health. Also Batenburg & Das (2014b) noted that participating frequently online was especially helpful for healthcare consumers who approach their emotions less actively. In addition, the relationship between online sources and well-being might be influenced by individual differences in coping styles (Batenburg & Das (2014a). In one case, health-related online support groups were even seen as "life-saving" during cancer survival (Dolce 2009). Takahashi et al. (2009) noticed that negative and egocentric comments were seen mostly as a psychological issue that might be bad for emotional or physical wellbeing (Gómez-Zúñiga et al. 2012, Shoebbotham & Coulson 2016, Takahashi et al. 2009). Finally, Gómez-Zúñiga et al. (2012) reported that those persons sharing health-related information on Youtube noted that loss of their privacy was a negative impact on their wellbeing, whilst the people behind the health-related online sources became targets of unwanted marketing.

Most of the consumers using health-related online sources agreed that the sites improved their ability to manage their own or their relative's illness, that is, cope with problems in their lives (for example, Gómez-Zúñiga et al. 2012, McKechnie et al. 2014, Wicks et al. 2010, Rupert et al. 2014). Consumers also reported that meeting other consumers made them feel less self-conscious about their condition, that the online source made them feel more in control of their condition and, finally, that the online source enhanced their quality of life (Shoebbotham & Coulson 2016, Wicks et al. 2012). Health-related online sources enabled more effective illness-related decision-making, since the majority of healthcare consumers found that online information had a significant influence on their decision-making (Black 2009). In some cases, patients managed their illness themselves having self-diagnosed it (Dolce 2009) or asking for help with the medicines from other healthcare consumers instead of healthcare professionals (Willis 2016).

In some studies, health-related online sources seemed to have an impact on the relationship between a healthcare organisation and its consumers (for example, Adams 2011, Dolce 2009, Loane & D'Alessandro 2014). Health-related online sources have been seen as a consumer's opportunity to make healthcare organisation or public health more transparent. One of the main purposes of rating websites is to increase the transparency of a healthcare organisation's policies and practices, making it respond to

publicly broadcast concerns and complaints (Adams 2011). Dissatisfaction with healthcare providers may be one reason to start using health-related online sources (Rupert et al. 2014). Also, stories about diagnostic failures are shared on health-related online sources (Dolce 2009) and, in some cases, discussions on those sites has brought about a change of doctor (Wicks et al. 2010, Wicks et al. 2012), or a demand to see another specialist (Wicks et al. 2012). Although some healthcare consumers are unhappy with their healthcare professional, many studies found that health-related online sources may also provide a better relationship between caregivers and healthcare consumers (Adams 2011, Wicks et al. 2012). According to Wicks et al. (2012), healthcare consumers reported receiving better care from healthcare professional after starting to use health-related online sources. On the other hand, Rupert et al. (2014) found cases where healthcare providers reacted negatively when the consumer mentioned online source usage. Finally, using the sources has a developmental impact on healthcare since it may make healthcare consumers more capable of evaluating the medical expertise and professional capabilities of a healthcare professional and, additionally, it may improve the quality of the care they receive (Adams 2011).

Discussion and conclusions

The aim of this research was to describe consumer-led health-related online sources and their impact on consumers. The number of scientific articles over the last five years describing research into health-related online sources have been rapidly increasing. At the same time, the impacts of online health sources on their users have also been explored, but there is a need to explore this area more effectively and deeper.

The main research approach used in the articles explored was qualitative. The predominant use of qualitative research could be because the phenomenon of health-related online sources is relatively new and qualitative research is flexible, capable of adjusting to new information (Polit & Beck 2012). In addition, there may only be a little quantitative data from the field, since there may be a lack of suitable standard measures and interpreting the data using those measures might be challenging. Identifying the data collection method was found to be complicated for some studies, as they did not strictly obey the basic rules of any of the data collection methods, because the data were derived from the internet. It should be noted that, as a research environment, the internet can be considered a new type.

When undertaking internet research, the use of complementary data analysing methods might be useful. Since it has been argued that online sources are a way for a consumer

to voice their opinions (Keeling et al. 2013), using analysis methods such as discourse or text analysis might offer significant results. Using these methods might be especially useful for research into rating websites or communities, which possibly include a great deal of data encapsulated in colourful speech, complex writing styles and interwoven contexts. Also, newer methods such as networking analysis and video analysis should be used more. One observation was that researching the combination of the internet and healthcare is multidisciplinary. It may even be that a new branch of science, which combines informatics and healthcare, is about to be born.

As Setoyama et al. (2011) and this review noted, research involving non-English speaking countries is limited. In this review, most of the studies explored countries where English was the primary language. The studies from English-speaking countries were most likely found because of the English language inclusion criteria. On the other hand, it should be noted that English-speaking sources may also include consumers from non-English speaking countries (Wicks et al. 2010).

In this review, three different kinds of health-related online sources were investigated as determined by the content analysis: health-related online communities, health-related rating websites and health-related social networking sites. These types of online sources were identified in research by Ziebland and Wyke (2012), who categorised some of the

well-known health-related online sources. In addition, they found general health information sites and blogs, which were not found in this review. The lack of health information sites might be explained by the year range used by this study since, as a phenomenon, these kinds of sites are not new and are thus already a lot researched. While searching data, some articles described traditional health information sites, but they were not included since they did not include information of these sites' impacts. Thus it can be asked, are the impacts of health information sites investigated enough? Usually, they were only explored from the viewpoint of secure and trustworthy information content. The lack of blogs and healthcare applications was surprising. There are plenty of blogs related to health (Ziebland and Wyke 2012) but the information retrieval did not include any articles that had researched just blogs and their impacts. Are blogs actually investigated or are they such a new phenomenon that they are still not found in searches? Unlike this review, Ziebland and Wyke (2012) categorised PatientsLikeMe as a consumer review/reputation site, whereas this review saw it used more as a illness-related community, unlike the rating websites which included little or no illness information. It should also be noted that there are many different names for the different sources so, for example, online communities may also be called forums or groups. Therefore, there needs to be standard terms applied to health-related online sources.

The primary impacts found in the studies exploring consumer-led health-related online sources, as noted in this review, are: empowerment, health literacy, physical, mental and emotional wellbeing, relationship between healthcare organisations and consumers, illness management and peer support. The studies carried out by Ziebland and Wyke (2012) and Barak et al. (2008) supported the impacts found. As Ziebland and Wyke (2012) found, so this study also found both negative and positive impacts. The negative impacts were that consumers felt that health-related online sources may create psychological issues through negative and egocentric comments and, in addition, they inflicted a loss of privacy. It is important to note that losing privacy occurs only in those cases where the consumer agrees to publish information under his/her own name. Usually, privacy site will offer the chance for a consumer to remain anonymous (Ziebland & Wyke 2012, McKechnie et al. 2014).

Health care organisations need to also take information related to negative impacts into account when developing services related to online sources. However, negative impacts have been little researched in comparison to positive ones (Eysenbach et al. 2004), possibly because previous studies only focused on positive impacts. However, the absence of evidence for negative impacts does not mean they do not exist. Thus, exploring the negative impacts is also important, especially in cases where they might cause great harm or risks to the health of the healthcare consumer or to others

(Eysenbach et al. 2004). Also, those impacts seen in a positive light might have a hidden dark side. Healthcare professionals are concerned that health-related online sources might become too trusted (Koch-Weser et al. 2012). They believe that internet information can often lead to consumers' becoming confused, distressed or misinformed and result in harmful self-diagnosis or self-treatment (Ahmad et al. 2006). Is it safe for non-healthcare educated consumers, who have comprehensive access to all health literature provided on the internet, to start diagnosing themselves or others (Giles & Newbold 2010)? Earlier studies have a disagreement if the healthcare consumers inform the healthcare professionals about the information picked from the Internet. The studies in this review showed that the use of online sources improved the relationship between the consumer and the healthcare professional (Adams 2011, Wicks et al. 2010, Loane & D'Alessandro 2014). However, some studies found that consumers preferred to hide internet-based information from their healthcare professionals (Diaz et al. 2002, Koch-Weser et al. 2012).

In contrast to this review, Bartlett & Coulson (2011) saw empowerment as a hyponym, causing further impacts such as health literacy and peer support. This review did not find that, but it is notable that empowerment was the most common emergent impact in the included studies (e.g. Loane & D'Alessandro 2014, Shoebbotham & Coulson 2016, Willis 2016) and it was often used in a context which implied that other things were

caused by it. Thus it can be questioned whether the empowerment is, as Bartlett & Coulson (2011) predicted, a major impact of health-related online sources that enables the other impacts or, as Barlett & Coulson (2011) called, “empowerment outcomes”. On the other hand, Johnston et al. (2013), whose main interest was empowerment as well, considered empowerment as a consequence of social support (cf. peer support). What is the relationship between impacts? Are some of them major impacts causing minor impacts?

Given that health-related online sources, in most cases, made healthcare consumers more competent actors and more aware of health issues, these sources may reduce consumers’ drifting among the healthcare services. If almost 70% of Scandinavians use the internet to improve or maintain their health (Wanberg 2009, .se 2012, Statistics Finland 2009), should also healthcare professionals, administrators and policymakers take advantage of this development? Healthcare consumers share their experience-based knowledge across the sources, in the process becoming experts or consultants whose knowledge might even be better than that of the healthcare professionals (Dolce 2009). At present, the information exchange occurs between healthcare consumers and consumer-led health-related online sources. The recommendation based on the results of this review is that healthcare organisations should become a part of this behaviour by providing health-related online sources as a part of their corporate strategy. By doing

this, healthcare organisations can become a part of this bidirectional information exchange, in which an organisation provides care for its consumers through trustworthy and safe information. According to Vennik et al. (2014) some healthcare consumers felt that the risk of getting untrustworthy information from the Internet could be reduced by getting the healthcare provider to participate in the conversation. In return, the organisation would receive valuable experience-based information from the consumers and possibly save resources. This is similar to the strategy of the site PatientsLikeMe – which is not only used inter alia for patient communication but also for providing data about the real-world nature of disease to help researchers, pharmaceutical companies, regulators, providers and non-profit organisations develop more effective products and care (PatientsLikeMe 2013). Finally, the internet, with its health-related online sources and ubiquitous nature, could offer a cost-effective base for low-threshold services by providing anonymity and 24 hours-a-day access.

As a whole, the use of online sources satisfied healthcare consumers' needs for a sense of community and emotional support (Shoebbotham & Coulson 2016, Zhao et al. 2015), as well as in terms of peer-support (McKechnie et al. 2014, Willis 2016). Health care organizations could use this information when developing services in times of scarcer resources towards providing more effective healthcare services. Studies show that this is also what patients would like. This kind of development work is even more justified

when the information available via online sources is of low quality (Cole et al. 2016), in the situation when consumers primarily search for deeper information via online resources (Rupert et al. 2014). This kind of development would challenge the traditional way of working in health care (Haukeland Fredriksen et al. 2016) and shift the usual relationship between patient and professionals into more of a partnership (Loane & D'Alessandro 2014). So the big question is, are health care organizations and professionals ready for this size of change in their activities?

Our conclusions are as follows:

1. The predominant use of qualitative methods might be explained as the phenomenon of online sources is a relatively new one and the need for greater information is required. Also, research into consumer-led health-related online sources is largely limited to the English-speaking population. It could be essential to develop standard measurements when obtaining quantitative data from online sources. These measures could be developed in a way that takes account of the differences (e.g. culture, age or illness) between consumers.
2. The knowledge of the existence of the sources provides healthcare organisations with an opportunity to listen to their consumers' "voice". More research from

the field of consumer-led health-related online sources is required, with it being important to define them and actively note new ones.

3. Healthcare consumers, as the users of consumer-led health-related online sources, are more competent and connected actors in regards to healthcare, even becoming experts who are capable of managing their illness. Their knowledge is a valuable resource for healthcare providers and policymakers that could be used more to develop better care.
4. Consumer-led health-related online sources have several positive impacts that might reduce the need for drifting among healthcare services and might save healthcare organisations' resources, should such companies incorporate these sites into their own corporate strategy. By doing this, an organisation could create a bidirectional channel with healthcare consumers, along which the healthcare organisation itself could transfer care and trustworthy information to its consumers. In return, consumers would offer their experience-based knowledge to the organisation. The internet might be useful in producing low-threshold services. The internet could provide the solution to many of the current problems with healthcare.

For future studies, the following subjects would of interest to research: more detailed information about health-related online sources and their positive and negative impacts; the organisational viewpoint of online sources, and the use of

health-related online sources among the non-English speaking population. In the future, research should analyse data collected from the internet more effectively.

Limitations

An integrative literature review has the following limitations. As is the case with most literature reviews, there remains the possibility that some relevant articles may have been overlooked, particularly if studies did not mention specific online sources. Additionally, choosing the correct search terms for the retrieval of information may have been unsuccessful and using electronic databases may have introduced errors because of differences between different databases. Only peer-reviewed studies were included and thus relevant studies classified as grey literature might have been excluded. Lastly, the researcher's lack of fluency in certain languages may have resulted in the exclusion of potential studies (n=32). Undertaking a literature review does not raise any ethical questions, since it analyses previously completed research and no participants in that research are ever contacted (Aveyard 2007).

References

Adams, S.A. (2011) Sourcing the crowd for health services improvement: The reflexive patient and “share-your-experience” websites, *Social Science & Medicine*, 72:1069–76.

Ahmad, F., Hudak, P.L., Bercovitz, K., Hollenberg, E. & Levinson, W. (2006) Are physicians ready for patients with Internet-based health information? *Journal of Medical Internet Research*, 8(3).

Akhu-Zaheya, L.M. & Dickerson, S.S. (2009) Jordanian patients' and caregivers' use of the Internet for seeking health information, *CIN COMPUT INFORM NURS*, 27(3):184–191

Andreassen, H.K., Bujnowska, M.M., Chronaki, C.E., Dumitru, R.C., Pudule, I., Santana, S., Voss, H. & Wynn, R. (2007) European citizens' use of E-health services; a study of seven countries, *BMC Public Health*, 7:53.

Aveyard, H. (2007) *Doing a Literature Review in Health and Social Care*, Open University Press, Berkshire.

Barak, A., Boniel-Nissim, M. & Suler, J. (2008) Fostering empowerment in online support groups, *Comput Hum Behav*, 24:1867–83.

Bartlett, Y.K., & Coulson, N.S. (2011) An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication, *Patient Education and Counseling*, 83:113–119.

Batenburg, A., & Das, E. (2014a) Emotional Coping Differences Among Breast Cancer Patients From an Online Support Group: A Cross-Sectional Study, *Journal of Medical Internet Research*, 16(2):e28 .

Batenburg, A., & Das, E. (2014b) Emotional Approach Coping and the Effects of Online Peer-Led Support Group Participation Among Patients With Breast Cancer: A Longitudinal Study, *Journal of Medical Internet Research*, 16(11):e256.

Bhandari, G. & Snowdon, A. (2012) Design of a patient-centric, service-orientated health care navigation system for a local health integration network, *Behav. Inform. Technol.*, 31(3):275–285.

Black, E.W., Thompson, L.A., Saliba, H., Dawson, K. & Black, N.M.P. (2009) An analysis of healthcare providers' online ratings, *Informatics in Primary Care*, 17: 249-53.

Camerini, L. & Schulz, P. J. (2012) Effects of functional interactivity on patients' knowledge, empowerment, and health outcomes: An experimental model-driven evaluation of a web-based intervention, *Journal of Medical Internet Research*, 14(4):60-75.

Cole, J., Watkins, C. & Kleine, D. (2016) Health Advice from Internet Discussion Forums: How Bad is Dangerous? *J Med Internet Res*, 18(1):e4 doi:10.2196/jmir.5051

Collins, S. & Lewis, D.M. (2013) Social Media Made Easy: Guiding Patients to Credible Online Health Information and Engagement Resources, *CLIN DIABETES*, 31(3): 137–141.

De la Torre-Díez, I., Javier, Díaz-Pernas J. & Antón, R.M. (2012) A Content Analysis of Chronic Diseases Social Groups on Facebook and Twitter, *Telemedicine and E health*, 18(6):404–408.

Denzin, N. K. & Lincoln, Y. S. (2011). *Handbook of qualitative research*, Thousand Oaks, CA:Sage.

Diaz, J.A., Griffith, R.A., Ng, J.J., Reinert, S.E., Friedmann, P.D. & Moulton, A.W. (2002) Patients' use of the internet for medical information, *Journal of General Internal Medicine*, 17(3):180–185.

Dolce, M.C. (2011) The Internet as a Source of Health Information: Experiences of Cancer Survivors and Caregivers With Healthcare Providers, *Oncology Nursing Forum*, 38(3):353–359.

Donelle, L. & Hoffmann-Goetz, L. (2009) Functional health literacy and cancer care conversations in online forums for retired persons, *Informatics for Health & Social Care*, 34(1):59–72.

Easterling, D.S. (2001) Virtual Community and Connections: Their Relevance to Health Care Marketing, *Journal of Nonprofit & Public Sector Marketing*, 8(4):75–89.

Evans, M., Donelle, L. & Hume-Loveland, L. (2011) Social support and online postpartum depression discussion groups: A content analysis, *Patient Education and Counseling*, 87:405–410.

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C. & Stern, A. (2004) Health related virtual communities and electronic support groups: systematic review of the effects of peer to peer interactions, *BMJ* 328.

Hanson, C. L., West, J., Thackeray, R., Barnes, M. D. & Downey J. (2014) Understanding and Predicting Social Media Use Among Community Health Center Patients: A Cross-Sectional Survey, *Journal of Medical Internet Research*, 16(11):e270.

Huang, K., Chengalur-Smith, I. & Ran, W. (2014) Not Just for Support: Companionship Activities in Healthcare Virtual Support Communities, *Communications of the Association for Information Systems* 34(29):561–594.

Haukeland Fredriksen, E., Harris J. & Moland K. (2016) Web-based Discussion Forums on Pregnancy Complaints and Maternal Health Literacy in Norway: A Qualitative Study, *Journal of Medical Internet Research*, 18(5):e113.

Gilbert, K., Dodson, S., Gill, M. & McKenzie, R. (2012) Online Communities Are Valued by People With Type 1 Diabetes for Peer Support: How Well Do Health Professionals Understand This? *Diabetes Spectrum*, 25(3):180–191.

Giles, D.C. & Newbold, J. (2011) Self- and Other-Diagnosis in User-led Mental Health Online Communities, *Qualitative Health Research*, 21(3):419–428.

Gómez-Zuñica, B., Fernandez-Luque, L., Pousada, M., Hernández-Encuentra, E. & Annayones M. (2012) ePatients on YouTube: Analysis of Four Experiences From the Patients Perspective, *Medicine 2.0*, 1(1): (page number not for citation purposes).

Houston, T.K. & Allison, J.J. (2002) Users of Internet health information: differences by health status, *Journal of Medical Internet Research*, 4(2):E7

Laing, A., Keeling, D. & Newholm, T. (2011) Virtual communities come of age: Parallel service, value, and propositions offered in communal online space, *Journal of Marketing Management*, 27:291–315.

Loane, S.S. & D'Alessandro S. (2014) Empowered and knowledgeable health consumers: The impact of online support groups on the doctor–patient relationship, *Australasian Marketing Journal* 22:238–245.

Lober, W.B. & Flowers, J.L. (2011) Consumer Empowerment in Health Care Amid the Internet and Social Media, *Seminars in Ontology Nursing*, 27(3):169–182.

Joanna Briggs Institute (2011) Reviewers' manual. Available at <http://joannabriggs.org/Documents/sumari/Reviewers%20Manual-2011.pdf> (Accessed October 21, 2013).

Johnson, D. & Lowe, B. (2011) Understanding consumer active participation in healthcare virtual communities, *American Marketing Association*, 331–332.

Johnston, A.C., Worrell, J.L., Di Gangi, P.M. & Wasko, M. (2013) Online health communities. An assessment of the influence of participation on patient empowerment outcomes, *Information Technology and People*, 26(2):213–235.

Josefsson, U. (2005) Coping with Illness Online: The Case of Patients' Online Communities, *The Information Society*, 21:143–153.

Keeling, D., Khan, A. & Newholm, T. (2013) Internet forums and negotiation of healthcare knowledge cultures, *Journal of Services Marketing*, 27(1):59–75.

Koch-Weser, S., Bradshaw, Y.S., Gualtieri, L. & Gallagher, S.S. (2010) The Internet as a health information source: findings from the 2007 Health Information National Trends Survey and implications for health communication, *Journal of Health Communication*, 15:279–93.

Kordzadeh, N., Liu, C., Au, Y. & Clark J. (2015) A Multilevel Investigation of Participation Within Virtual Health Communities, *Communications of the Association for Information Systems*, 24(26):493–512.

McKechnie, V., Barker, C. & Stott, J. (2014) The Effectiveness of an Internet Support Forum for Carers of People With Dementia: A Pre-Post Cohort Study, *Journal of Medical Internet Research*, 16(2):e68.

Morgan, T., Schmidt, J., Haakonsen, C., Lewis, J., Rocca, M. D., Morrison, S., Biesecker, B. & Kaphingst, K. A. (2014) Using the Internet to Seek Information About

Genetic and Rare Diseases: A Case Study Comparing Data From 2006 and 2011, *JMIR Res Protoc* 2014, 3(1):e10.

NHS (National Health Service) (2012) Future Forum Report on Information, Available at <http://healthandcare.dh.gov.uk/forum-report/> (Accessed January 15, 2014).

Newbold, D. & Hyrkäs, K. (2010) Managing in economic austerity. Editorial. *Journal of Nursing Management*, 18:495–500.

O'Neill, B., Ziebland, S., Valderas, J. & Lupiáñez-Villanueva F. (2014) User-Generated Online Health Content: A Survey of Internet Users in the United Kingdom, *Journal of Medical Internet Research*, 16(4):e118.

Polit, D.F. & Beck, C.T. (2012) *Nursing Research. Generating and Assessing Evidence for Nursing Practice*, Wolters Kluwer Health, Lippincott Williams & Wilkins, Philadelphia.

PatientsLikeMe (2013) About us, Available at <http://www.patientslikeme.com/about> (Accessed December 15, 2013).

Rooney, K. (2009) Consumer-driven healthcare marketing: using the Web to get up close and personal, *Journal of Healthcare Management*, 54(4):241–251.

Rupert, D.J., Moultrie, R.R., Read, J.G., Amoozegar, J.C., Bornkessel, A.S., O'Donoghue A.C. & Sullivan H.W. (2014) Perceived healthcare provider reactions to patient and caregiver use of online health communities, *Patient Education and Counseling*, 96(3):320–326.

Van Uden-Kraan, C.F., Drossaert, C.H.C., Taal, E., Shaw, B.R., Seydel, E.R. & van de Laar, M.A.F.J. (2008) Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis or fibromyalgia, *Qualitative Health Research*, 18:405–417.

Vennik, F.D., Adams, S.A., Faber, M.J. & Putters K. (2014) Expert and experiential knowledge in the same place: Patients' experiences with online communities connecting patients and health professionals, *Patient Education and Counseling* 95: 265–270.

Wald, H.S., Dube, C.E. & Anthony, D.C. (2007) Untangling the Web – the impact of Internet use on health care and the physician-patient relationship, *Patient Education Counseling*, 68:218–224.

Wangberg, S., Andreasen, H., Kummervold, P., Wynn, R. & Sørensen, T. (2009) Use of the internet for health purposes: trends in Norway 2000-2012, *Scandinavian Journal of Caring Sciences*, 23(4):691–696

Wicks, P., Massagli, M., Frost, J., Brownstein, C., Okun, S., Vaughan, T., Bradley, R. & Heywood, J. (2010) Sharing Health Data for Better Outcomes on PatientsLikeMe, *Journal of Medical Internet Research*, 12(2):e19.

Wicks, P., Keininger, D.L., Massagli, M.P., de la Loge, C., Brownstein, C., Isojärvi, J. & Heywood, J. (2012) Perceived benefits of sharing health data between people with epilepsy on an online platform, *Epilepsy & Behavior* 23:16–23.

Willis, E. (2016) Patients' self-efficacy within online health communities: facilitating chronic disease self-management behaviors through peer education, *Health Communication*, 31(3):299–307.

Whittemore, R. & Knafl, K. (2005) The integrative review: updated methodology, *Journal of Advanced Nursing*, 52(5):546–553.

Setoyama, Y., Yamazaki, Y. & Namayama, K., (2011) Benefits of Peer Support in Online Japanese Breast Cancer Communities: Differences Between Lurkers and Posters, *Journal of Medical Internet Research*, 13(4):e122.

.se (2012) Swedes and the Internet 2012. .se Internetstatistics, Available at <https://www.iis.se/docs/Swedes-and-the-Internet-2012.pdf> (Accessed December 10, 2013).

Shoebatham, A. & Coulson, N.S. (2016) Therapeutic Affordances of Online Support Group Use in Women With Endometriosis, *Journal of Medical Internet Research*, 18(5):e109.

Sittig, D.F., King, S. & Hazelhurst, B.L. (2001) A survey of patient-provider e-mail communication: What do patients think? *International Journal of Medical Informatics*, 61(1):71–80.

Takahashi, Y., Uchida, C., Miyaki, K., Sakai, M., Shimbo, T., & Nakayama, T. (2009) Potential Benefits and Harms of a Peer Support Social Network Service on the Internet

for People With Depressive Tendencies: Qualitative Content Analysis and Social Network Analysis, *Journal of Medical Internet Research*, 11(3):e29.

Statistics Finland (2009) Internetin käyttö on yleistä ja arkista, Available at http://www.stat.fi/artikkelit/2009/art_2009-09-30_007.html?s=0 (Accessed December 10, 2013).

Taylor, H. (2012) “The growing influence and use of health care information obtained online”, Harris Interactive, Available at www.harrisinteractive.com/vault/HI-Harris-Poll_Cyberchondriacs-2011-09-15.pdf (Accessed January 14, 2014).

Terlutter, R., Bidmon, S. & Röttl J. (2014) Who Uses Physician-Rating Websites? Differences in Sociodemographic Variables, Psychographic Variables, and Health Status of Users and Nonusers of Physician-Rating Websites. *Journal of Medical Internet Research*, 16(3):e97.

Thielts, C.B. (2011) Social Media: Ubiquitous Community and Patient Engagement, *Frontiers of Health Service Management*, 28(2):3–14.

Samson Institute (2013) Critical appraisal tools, Available at <http://www.unisa.edu.au/Research/Sansom-Institute-for-Health-Research/Research-at-the-Sansom/Research-Concentrations/Allied-Health-Evidence/Resources/CAT/> (Accessed October 15, 2013).

Ye, Y. (2014) The Role of Illness Factors and Patient Satisfaction in Using Online Health Support Groups, *Health Communication*, 29(4):355–363.

Ziebland, S., Chapple, A., Dumelow, C., Evans, J., Prinjha, S. & Rozmovits, L. (2004) How the internet affects patients' experience of cancer: a qualitative study, *BMJ*, 6: 328:1–6.

Ziebland, S. & Wyke, S. (2012) Health and Illness in A Connected World: How Might Sharing Experiences on the Internet Affect People's Health? *The Milbank Quarterly*, 90(2):219–249.

Zhao, J., Wang T. & Fan X. (2015) Patient value co-creation in online health communities: social identity effects on customer knowledge contributions and membership continuance intentions in online health communities, *Journal of Service Management*, 26(1):72–96.