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UNDERSTANDING INFORMATION USE IN ONLINE CONSUMER-HEALTH SUPPORT GROUPS: A LOOK INTO INTERACTIVE HEALTH COMMUNICATIONS

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ABSTRACT

The exponential growth of the Internet in the past two decades has been accompanied by an increased interest by Internet users in communicating among each other electronically about all sorts of topics, including health-related issues. This increased interest in peer-to-peer communication for health topics raised lots of questions about the potential harmful effects of these communications on those participants who might take some health-related action without consulting with a doctor first. This potential problem has motivated the researcher to investigate how people with certain health conditions use health information that they obtain from online support groups.

Even though the understanding of how information is sought, retrieved, and ultimately used is a very important topic within information behavior research, information use is an area that has seen less study. For this reason, the researcher decided to investigate information use within online consumer health support groups using a content analytical approach. The study had two specific objectives: (a) to describe what some of the cognitive, affective, and behavioral actions that consumers indicate they had taken based on information shared within some of the online support groups to which they belong; and (b) to determine if the uses given to information follow any pattern among different chronic conditions being studied with relation to the type of questions asked, the type of reply messages, and the health-related content of the messages.

Methodologically, the study used computer-mediated discourse analysis to guide collection of trace data that came from archives of selected online discussion boards related to the three chronic conditions chosen for the study. For data to be part of the study, the presence of interactions with indications of usefulness was necessary. Then, through content analysis, the data was coded using several classification schemas found in the literature, some of them in their original form, others adapted to fit this research purpose. These schemas looked into the types of questions asked, the functions of the reply messages, the type of medical content of the posted messages, and the type of use given to the information. Once all the data was processed, the researcher looked for patterns among the different variables and across the different gender-based chronic conditions.

Results of the analysis show that the message characteristics of content type, function of reply messages, and question types, have a significant relationship with the types of conditions. Message characteristics also show a significant relationship with the cognitive, affective, and behavioral information uses. Discussions of the results as well as some alternatives for future research are presented.

UNDERSTANDING INFORMATION USE IN ONLINE CONSUMER HEALTH SUPPORT GROUPS: A LOOK INTO INTERACTIVE HEALTH COMMUNICATIONS

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1.1. INTRODUCTION

In the last two decades, the number of U.S. adults using Internet technology information grown continually, from about 44% in 2004 to 87% in 2014. At the same time, there has been continual growth in users' interest in communicating with other peers online for all sorts of topics (Humphrey, 2011; Hu, Bell, Kravitz, & Orrange, 2012; Fox, 2013; NTIA & ESA, 2013).

This increased interest in online communication among peers and the increased availability of computer-mediated communication tools, has given rise to the wide spread popularity of electronic support groups via mailing lists, newsgroups, bulletin boards, and more recently, of social media technologies such as Twitter and Facebook (Madara, 1997; Lewis, 1998; Nickelson, 2000; Zrebiec & Jacobson, 2001; Fox, 2013; Attrill, 2015; Wright, 2016).

Some researchers report that not only has the popularity of online support groups (OSGs) increased, from several thousands of groups to hundreds of thousands of groups (Fox & Duggan, 2013; NationalCancerInstitute, 2013), but these groups have significantly influenced the ways that patients manage their health issues and how they interact with their health care providers (Van Uden-Kraan et al., 2009;

Barlett & Coulson, 2011; Lee, Hoti, Hughes, & Emmerton, 2014b). For example, Hu et al. (2012) reported that proliferation of support groups online could be seen in the number that were listed in the Yahoo Health & Wellness directory, which was about 12,392 groups at that time. More recently, as of March 2015, this number has grown to about 40,013 groups. Other researchers (Fox & Duggan, 2013; NationalCancerInstitute, 2013) suggest that the increased number of OSGs has gone from several thousand groups to hundreds of thousands of groups.

In addition, looking into studies and recent surveys about Internet use (Fox, 2013; Kammerer, Braten, Gerjets, & Stromso, 2013; NTIA & ESA, 2013), researchers seem to agree that one of the major topics that people research online every day is health information. In fact, as reported by Cole, Watkins and Kleine's (2016), 80% of Internet users search online to find health information, which includes participation in different types of online interaction (newsgroups, bulletin boards, chat rooms, mailing lists, for example), 60% of them indicated the information found online affected a decision about how to treat a medical condition, and 41% indicated that they or somebody they know had been helped by following medical advice found online. Researchers have also found that people with disabilities or chronic and stigmatizing conditions are more likely to look for health information online (Davison, Pennebaker, & Dickerson, 2000; Hu et al., 2012; PewResearchCenter, 2014). More specifically, it was reported that

"53% of adults with one or more chronic conditions have looked online for health information" (PewResearchCenter, 2014, p. 6). Similarly, those individuals with a larger number of unmet health information needs were more likely to participate in online support groups providing health information and social support (Lee & Hawkins, 2010; Tustin, 2010).

It is important to notice that 'information behavior' is a complex phenomenon which, even though is not new and has been studied from most perspectives of the information-seeking process, including research on people's searching strategies, people's communication behavior, the effect of situational variables, and information use environments (Dervin, Harlock, Atwood, & Garzona, 1986; Taylor, 1991; Schoch & White, 1997), among others. But one of the aspects of information behavior that has not been studied as much or as deeply, as has been suggested by some researchers (Dervin & Nilan, 1986; Vakkari, 1997; Zrebiec & Jacobson, 2001; Bauerle Bass, 2003; Forkner-Dunn, 2003; Klemm et al., 2003; Spink & Cole, 2006; Raya, 2012), is information use/utilization. This need is nicely described by statements such as those of Wilson and Walsh's (1996) where they assert that:

> The fact that a situation demands information to fill cognitive gaps, to support values and beliefs, or to influence affective states, and that sources of information are available and accessible … is not guarantee that the information will be processed or used. (p. 1)

More specifically, in this era of social media sharing and interaction, this lack of research about how information is used can be observed within the context of online health message boards as observed by (Macias, Stavchansky, & Smith, 2005; Pang, Verspoor, Chang, & Pearce, 2015). This research agrees with Bauerle Bass et al.'s (2006) assertion that:

> The results of this study, along with those conducted with similar patient populations, should encourage researchers to study how interactive technologies might be used to benefit patients with serious and life-threatening conditions and how their use might change patient behavior. (p. 232)

And Bartlett and Toms's (2013) indicate that:

> "Information Science often stops short of examining what people do with the information once it has been received and how it is applied to accomplishing a specific task or goal" (p. 1).

Thus, since health information is such an important motive for people to search online, and given the widespread popularity of online communication tools, understanding the significance and impact that the use of information from Internet sources may have on the health of individual citizens has become a major interest for government agencies, legislators, and researchers (Rosembaum, 2010; Humphrey, 2011; Lustria ML, Smith SA, & CC, 2011; HHS, 2014). As a result, and as suggested by numerous researchers (Evers, Prochaska, Driskell, Cummins, & Velicer, 2003; Shultz, Stave, Beck, & Vassilopoulou-Sellin, 2003; Hong, Peña-Purcell, & Ory, 2012; Hu et al., 2012; Savolainen, 2015), we need a better understanding of consumers' health information behavior using online sources, and it is the main topic of this investigation.

This chapter will provide an overview of the research presented here. More specifically, this dissertation investigates what we know about the nature of consumer health information use from online discussion boards, presented through an introduction, a problem rationale, an overview of the literature, research questions, methodology, major contributions, and limitations of the study.

At a general level, the goal of this study was to further understand how consumers are actually using health information they received within online support groups in response to questions they asked. At a more specific level, this goal was translated into the following objectives: Describe what some of the cognitive, affective, or behavioral actions that health consumers indicated they have taken as a result of information shared within the online support groups to which they belong, and determine if the uses of this information follow any patterns among groups exhibiting different chronic conditions, with relation to the types of content searched and used and the types of question that are asked with relation to the types of reply messages that are received.

The results of this study contribute to the understanding of activities that go beyond the information-seeking process, namely, the use information, which could aid in the design and testing of web information systems, question-answering services, and portals to more accurately satisfy users' needs. Within the health information arena, contributions are expected to aid in the design of better and more tailored consumer-education materials as well as increase health consumers' awareness of how participation in these online communities can help them and others to improve their health outcomes, even in spite of the fact that incorrect or malicious information is sometimes distributed through this medium.

1.2. RATIONALE OF THE PROBLEM

Over the years, numerous research studies have paid attention to understanding: the information needs of scientists, citizens, and engineers, among other scholars; the patterns of information-seeking behavior of end users, use of information systems by end users; users' preferences and use of varying sources of information; barriers to the use of information systems; and other information-seeking and use-related issues within several different population sectors—including government, education, scientific research, organizations, medicine, science and technology (Legris, Inghamb, & Collerettec, 2003; Spink & Cole, 2006; Case, 2012; Hu et al., 2012; Lee et al., 2014b). However, systematic research concerned with the actual uses of information—online health information in particular—have not received lot of attention up until recently (Dervin & Nilan, 1986; Vakkari, 1997; Longo, Patrick, & Kruse, 2001; Savolainen, 2001; Zrebiec & Jacobson, 2001; Klemm et al., 2003; Grimsbo, Engelsrud, Ruland, & Finset, 2012; Mishra, Allen, & Pearman, 2014; Cheong-Iao Pang, Verspoor, Chang, & Pearce, 2015).

There have been a great number of studies on information use by specific populations and professions, but they really have not told us very much about the actual use of information, as some key researchers have pointed out (Taylor, 1991; Wilson, 1997b). A few studies have done empirical research in areas related to this study that focus on: uses of health information provided by health libraries, consumer health information services and their impact on health consumers' perceptions, the degrees in which health information was helpful in various situations, and general aspects of the information-seeking behavior of healthcare scientists and providers (Dervin et al., 1986; Marshall, 1992; Pifalo, Hollander, Henderson, DeSalvo, & Gill, 1997; Detlefsen, 1998; Baker & Pettigrew, 1999; Sweetland, 2000; Nicholas, Huntington, Williams, & Gunter, 2003; Hu et al., 2012; Pang et al., 2015).

Other studies related to online support groups, such as (Hall, 1981; Klemm, Reppert, & Visich, 1998; Klemm, Hurst, Dearholt, & Trone, 1999; White & Dorman, 2001; Sullivan, 2003; Owens et al., 2010; Wang, Kraut, & Levine, 2012; Biyani, Caragea, Mitra, & Yen, 2014), focused on patterns in the use of information, gender and cultural differences in terms of the type of messages exchanged, emotional and informational support, and implications of online support for health education, but not specifically on the actions, thinking, and feelings that occur after the information is put to use by the health consumers.

1.2.1. UNDERSTANDING IMPORTANCE OF ONLINE HEALTH INFORMATION

Even though many previous studies suggest online health information is of poor quality, others indicate that much less actual evidence of poor information leading to inappropriate health decisions has been found (Crocco, Villasis-Keever, & Jadad, 2002; Eysenbach & Kohler, 2002; Bansil, Keenan, & Gilliland, 2006; Nolke, Mensing, Kramer, & Horngerb, 2015). And as reported by Cole et al. (2016), even fewer studies have “focused on how likely it is that Internet discussion forum readers will take action based on the information they found there” (p. 3).

Fortunately, things are changing, and lately more emphasis has been given to understanding the rationale behind the increasing amount of searching people are conducting and their increased use of the Internet for health purposes. This includes studies in a variety of themes, such as how people assess quality and accuracy of online health information (Eysenbach, 2002; Bates B, Romina S, Ahmed R, & D, 2006; Ye, 2011; Lee, Hoti, Hughes, & Emmerton, 2014a), how people use health websites, health information services, health kiosks or patients' experiences using interactive health communication applications (Eysenbach, 2003; Nahl, 2007a; Grimsbo et al., 2012; Parthasarathy & Fang, 2013; Kontos, Blake, Chou, & Prestin, 2014), what kinds of health-related questions health consumers ask (Roter, 1984; White, 1998b, 2000; Slaugther, 2002; Crangle & Kart, 2015), risks and issues of patients using online health information without discussing it with their physicians (Gustafson, Robinson, Ansley, Adler, & Brennan, 1999; Crocco et al., 2002; Gualtieri, 2009); patient empowerment (Van Uden-Kraan et al., 2009), patterns of support group participation, thematic analysis of experiences by gender (Malik & Coulson, 2008a; Mo, Malik, & Coulson, 2009), types of outcomes from OSGs (Davison et al., 2000; Coulson, Buchanan, & Aubeeluck, 2007), aspects of health information literacy within OSGs (Yates, Stoodley, Partridge, Bruce, & Cooper, 2012), and the role of information use in illness representations and in coping (Malik & Coulson, 2010; Chen, 2014).

The extraordinary growth of online health information use is highlighted by the more recent statistics from Pew Internet Research Center (Fox &

Duggan, 2013), which indicate that of the estimated 87% of U.S. adults that use the Internet, about 72% reported they have gone online for health information, 35% of them have gone online specifically to figure out a medical condition that they or someone else might have, and 24% of them have received information or support from others who have the same health condition.

Of the people that went online for health information, percentages were evenly split at 36% for those who wanted information related to their own situation and those who wanted the information for someone else's medical situation; 15% reported they looked for information for both themselves and others. These facts and the steady rise of health consumers' participation in online support groups, as described by (White & Dorman, 2001; Zrebiec & Jacobson, 2001; Klemm et al., 2003; Johnson & Ambrose, 2006; PewResearchCenter, 2014), support Dervin's (1976) claim that the way information is transmitted by formal channels rarely coincide with the way people want or use information, meaning that the ways people get information from formal sources such as books, journals, and their health practitioners do not exactly coincide with the more interactive ways that people currently use to get information, as for example, through informal channels such as OSGs.

1.2.2. WHY IS IT IMPORTANT TO UNDERSTAND HOW CONSUMERS ACTUALLY USE HEALTH INFORMATION OBTAINED ONLINE?

In spite of the extensive research on aspects of information seeking and use mentioned above, several researchers within information science and consumer health areas continue to point out that health information use by lay people has received little attention and that there is a need for further understanding about how health consumers actually use information and their experiences with the sources—that is, what do they think, how do they emotionally react, and what actions do they take after using online information (Dervin & Nilan, 1986; Eysenbach, 2003; Spink & Cole, 2006; Higgins, Sixsmith, Barry, & Domegan, 2011; Zhang & Fu, 2011; Kelly, Jenkinson, & Ziebland, 2013; Fiksdal et al., 2014; Stommel & Lamerichs, 2014).

According to Sundar, Rice, Kim and Sciamanna's (2011), “The design and effectiveness of online health information measures depends heavily on a clear understanding of users and their use patterns” (p.189). Also, as Kollock and Smith's (1999) suggest, “Technology has its most profound effect when it alters the ways in which people come together and communicate” (p. 4) and that is precisely what Internet-related technologies have done. They have changed the ways we communicate, search for information, share information with others, and interact with other people in what are now known as virtual communities. More specifically, technology is also changing the nature of interactions between individuals and health professionals. This suggests that now that more people go online for health information and support, it is important that doctors and other medical professionals understand how patients use that information to support their decision making so that, as reported by Ridings and Gefen's (2004) they can “make them equal partners in the care” (p.49).

The problem at issue here is that, in terms of the information exchange value, we know little about how Internet-related technologies, such as online discussion boards, are influencing the ways in which the information exchanged is actually being used and whether this information has had any effect on people’s health outcomes (Risk & Petersen, 2002; Silence, 2013).

As reported by Kienhues and Bromme's (2012), since “lay people do not have substantial knowledge or experiences themselves, they have to rely on others to justify their beliefs” (p. 4). Those others are peers who have already experienced a particular disease and not only “usually know better what to do than physicians” (Kienhues & Bromme, 2012, p. 5) in terms of strategies for coping with daily health issues, sharing their experiences and trajectory with the disease, but also, because they create a sense of comradery, as they are going through the same health challenge together—that they are not alone (Newman, Lauterbach, Munson, Resnick, & Morris, 2011). This is another reason why it is important to understand how information exchanged in online support groups is used.

Another good point about why it is important to understand how health information from online support groups is used by health consumers is that since “all online spaces people use exert influence on the choices that people make in those spaces” (Munson, Cavusoglu, Frisch, & Fels, 2013, p. 4), then, as suggested by Cole et al.’s (2016) study, “the more designers, owners, operators and users of online discussion are aware of what these influences are likely to be, the more able they will be to consider how they can influence users’ choices” (p. 2).

As the number of people participating in online communities continues to increase, and online interactions become even more important, understanding how those interactions influence participants’ actual uses of information becomes very important for future enhancement of that technology, for the information providers, for web system designers, and for the participants of those communities themselves. In some cases, such as those related to online interactive communications, actual uses of information have the potential to become a threat or even to cause harm to participants (Robinson, Patrick, Eng, & Gustafson, 1998) and there will be not much that others can do to help. In cases of nonmedical information use, even though participants might give a lot of credibility to online information, the consequences they will face if it is bad information might not be that problematic. Still in both cases, research shows that if participants' online information behaviors were known, it would give information providers and policymakers better baseline data to ensure information is used properly and safely, and that consumers' decisions don't get negatively influenced by online information that might be of dubious quality (Berland et al., 2001). As some researchers point out, there is no question that people are accessing Internet health information and acting on it, but the problem is that "little is known empirically, about how Internet use correlates with patient behavior characteristics, perceived self-efficacy, or other psychological variables, especially when a person is diagnosed with a serious or life threatening disease" (Bauerle Bass et al., 2006, p. 3).

As reported in the consumer health information (CHI) literature, online support groups are an important source that Americans use to make changes in their health behaviors (Larkin, 2000; Fox & Fallows, 2003; Fox & Duggan, 2013), so it is vital that we understand not only how much of an impact these online support groups can make on health but also identify what those changes really are by directly observing the online communications that motivate behavioral uses of information, and as pointed out by Wright and Bell's (2003), compare different types of groups for specific health conditions.

1.3. MEANING OF INTERACTION FOR THIS RESEARCH

Even though several definitions of interactivity were found, as reported by McMillan and Hwang's (2002), little consensus has been reached regarding an overall definition. Similarly, Stromer-Galley's (2004) indicates that “the concept of interactivity is confusing because it refers equally to two phenomena: the one of interaction between people as well as that of interaction between people through mediated channels” (p. 391). This research will focus on the second phenomenon.

One definition that describes the second phenomenon is that of Rafaeli's (1988). His definition states that “interactivity is feedback that relates both to previous messages and to the way previous messages related to those preceding them” (p. 120). One of the features of interactivity that several researchers indicate is a sign of full interaction is that the roles of sender and receiver are interchangeable and freely reversible (Stromer-Galley, 2004) and this is precisely one of the types of information exchange that is facilitated by online bulletin boards such as the ones being studied here. Another feature of interactivity as Rafaeli's (1997) study indicates is that even though “interactive messages may be more agreeable than average, they will also tend to be more opinionated, humorous, self-disclosing and community oriented” (p. 6).

One other condition for interactivity suggested by Jones's (1997) study is that “there should be a variety of communicators” meaning that “if there is only one communicator there can be no interactivity” (p. 6). In other words, for interaction to occur there must be an exchange of information, ideas, or opinions and some feedback response between two or more participants, either in person or through the use of a computer-mediated communication channel.

Good places to find those interactions are virtual communities, such as traditional, structured message boards. They depend upon social interaction and exchange between online users, and they emphasize the unwritten element of expected reciprocity (Kollock & Smith, 1999). Under this umbrella of expected reciprocity, participants in online support groups tend to engage in request-feedback interaction cycles with fellow members under the notion of a general norm of community that says, “whatever is given ought to be repaid, if only to insure that more is available when needed” (Wellman & Gulia, 1999, p. 176). The problem with this notion within virtual communities is that most interactions take place among weak ties, which are not grouped into densely knit structures that enforce norms of reciprocity (Wellman & Gulia, 1999; Savolainen, 2001). In fact, this lack of reciprocity is considered one of the disadvantages of online communities (as described in Section 2.5.3).

1.4. CONTEXT OF THE STUDY

The philosophical assumption underlying this study is that it is retrospective, interpretative research as applied to the understanding of information use/utilization in online virtual health communities. “The interpretative research approach generally attempts to understand phenomena through the meanings people assign to them” (Walsham, 1993, p. 4). The research is considered retrospective because it has already occurred at the time of the data collection. This type of study allowed the investigator to formulate ideas about possible associations and potential relationships between the different variables of the study.

In this case, the research looked to understand health consumers’ information use behaviors by analyzing thoughts, feelings, and actions as expressed in their postings within online support groups. As Erdelez's (1995) research pointed out, incorporating cognitive, affective, and behavioral aspects of information users allows for a more complete understanding of users’ information behaviors.

1.5. APPROACH TO THE STUDY

The conceptual approach for this research is based on the framework of ecological constructionism. The model as described by Nahl's (2007a) is a threefold taxonomical approach motivated by the growing importance of understanding how people actually process information in context, and where information behaviors can be classified into three biological channels which include cognitive, affective and sensorimotor activities.

The study also followed two alternative assumptions proposed by Dervin and Nilan's (1986) research study:

> *"The Situationality assumption:* predicting and understanding how people use information and cope with events must be based on their perceptions of how they see the situation they are in" (p. 592)…
>
> *"The Uses assumption*: no matter what the intent of the source, receivers will make use of messages in terms of the helps they are seeking for the situations they are in" (p. 592).

These two assumptions led the researcher to decide to retrieve and keep together complete threads[1] of each conversation in order to have the best chance to identify the situation that might have led a participant to use information provided in the discussion board, regardless of the intention of the person who posted it. As pointed out by Coulson's (2005), using threads allows one to "gain a richer understanding of the context in which the support was given and the reactions of the message recipients" (p. 584).

1.6. GENERAL RESEARCH QUESTIONS

When trying to understand online health information use behavior, we realized that in the same way that the focus of information systems shifted

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[1] A bulletin board thread consists of a series of messages/replies that spring from an original post with all responses bounded together.

from a system-centered approach to a user-centered approach, the way health consumers make decisions about their health now has also been changing, from a focus on formal sources such as library resources that have a provider to consumer perspective to a more independent online/peer-to-peer, experience-sharing perspective. These informal sources such as OSGs are convenient and can also be very useful in facilitating an individual's connection to larger groups of people with the same health concerns and who could potentially help them solve their information needs. But since gathering information alone does not guarantee that information will be used or whether it will have a positive effect on health outcomes, it becomes important look into:

- What is the role that peer-to-peer interaction plays in helping health consumers to perform information use behaviors that can affect their health outcomes?

- What factors seem to contribute to different health behavior outcomes?

1.7. OVERVIEW OF CURRENT RESEARCH

In a previous review of relevant literature on people's information behaviors it was found that almost two decades ago, people tended to largely rely on interpersonal networks of family members, friends, colleagues, or acquaintances (Urfels, 2000) for good sources of health information. Other previous studies were mostly concerned with the use of information sources and systems—external behaviors—rather than with human aspects of information use or their effect on consumers—internal behaviors (Dervin & Nilan, 1986; Sweetland, 2000; Wilson, 2000; Bauerle Bass, 2003).

Some of the available research studies discuss different aspects of information searching, such as to what extend the search is affected by gender (Mo et al., 2009; Hu et al., 2012), topic, and possibly by the nature of the health situation (chronic condition, acute condition) being researched (Gantz, Fitzmaurice, & Fink, 1991). Other researchers have focused on the motivations for using online support groups and what kinds of support and information they provide (Van Uden-Kraan et al., 2009; Barlett & Coulson, 2011; Lee et al., 2014b).

More recently, with the abundance of online health information and the rise of social media interaction, there has been more interest by researchers on consumer health in general as well as in studies of online interactions (Moorhead et al., 2013; Sillence, 2013; Chung, 2014; Lee et al., 2014b, a; Mattsson, Gustaf-Olsson, Alfonsson, Johansson, & Carlsson, 2015; Cole et al., 2016; Wright, 2016) which is why this research focus was to understand health consumers' information use behaviors within online health support groups.

Despite the fact that social networking sites' popularity continues to increase for all sorts of topics, (Kitzmann, Hermkens, McCarthy, & Silvestre, 2011), and that as reported by Moorhead's et al., (2013) study "social media is changing the nature and speed of health care interaction between individuals and health organizations" (p. 4), there is still limited evidence of how effective using peer-to-peer information & support provided through these applications can be to make a positive impact on people's health, which is why this research focus was to understand health consumers information use behaviors within online health support groups.

1.8. OVERVIEW OF METHODOLOGY

This study used computer-mediated discourse analysis to guide which observations were to be considered part of the data (data collection process) and how to look at the data to interpret the results (data analysis process). The basic orientation of computer-mediated discourse is language-focused content analysis, which, according to Pfeil and Zaphiris's (2010), is "one of the most commonly applied methods when investigating messages within online communities" (p. 7).

Content analysis was used on the contents of archived postings from selected online support groups, allowing the researcher to summarize the data, to measure the extent to which categories from the schemas appear in the communication content, and to make replicable and valid inferences while seeking objective answers to research questions (Krippendorff, 1980; Weber, 1990; Anderson, Dewshirst, & Ling, 2006). This technique is commonly used by researchers doing Internet-related research, and in particular, by those looking at online support groups (Schoch & White, 1997; Klemm et al., 1999; McTavish, Pingree, Hawkins, & Gustafson, 2003; Tichon & Shapiro, 2003; Macias et al., 2005; Coulson et al., 2007) because it allows for a more natural and less intrusive observation of online information behavior phenomena. For this research in particular, qualitative content analysis was used since the focus of the study was to understand the meaning of the data. Nevertheless, some basic statistics were also part of the analysis.

The coding schemas used in this research were selected a priori from some found in the literature. These coding schemas looked at the types of questions asked, the functions of the reply messages, the type of health content in a message, and the type of use given to the information. (Details about the selection of the schemas is explained in Section 3.6)

1.9. SIGNIFICANCE OF THE STUDY

This research brings together several lines of work from library and information science research, consumer health information, and online communities to give better understanding of the information use behaviors of participants in online health support groups.

Contributions in the area of information science include providing an improved understanding of a process that goes beyond the widely studied information-seeking activities, namely information use, within the specific context of online health support groups. Moreover, as stated by (Westbrook, 1993; Wilson, 1994; Booske & Sainfort, 1998), understanding how people use information and measuring information use is essential to aid questioning by intermediaries, or in the successful design and testing of more effective interfaces for human-computer interaction that are able to satisfy users' needs. As Costigan's (1999) puts it, "We are still at the point where we have to gain a better understanding of the trees themselves, before the forest makes any sense" (p. XXIV).

In health-related areas, this study could allow providers and patient-educators to design more effective teaching strategies and better ways to improve health consumers' compliance, thus improving quality of life. Similarly, as Johnson and Ambrose's (2006) suggest, this better understanding can allow providers to see the need to cultivate patients' participation in these health communities. The study can also be helpful to the development of preventive health intervention measures by people who are taking health-related actions themselves, and to awareness among health consumers of other possible uses that they can put the information to and gain health benefits.

CHAPTER SUMMARY

This chapter aimed to give some clarity to what it is known about how health consumers actually make use of health information. Definitions of a few key terms were presented here—other terms are included in the appendix—followed by the rationale of the study, the research questions, overviews of current research, and the methodology used. The chapter ended discussing the significance of the study.

CHAPTER 2: LITERATURE REVIEW

2.1. INTRODUCTION

The literature reviewed here describes research published in the library and information science area, as well as in the consumer health literature on the topic of health information use behaviors by lay health consumers.

Studies of information behavior in general cover a wide range of activities, including information seeking, information retrieval, information storage, information management, and information use, which is the main focus of this study. A few papers have looked at the intersection of medicine and information behaviors but most of them are out of date. Among recent studies, only a few have looked at information use from the perspective of interactive online communication.

Previous studies related to information use were about how physicians used the Internet for their information needs or doctor-patient interactions (Osiobe, 1985; Verhoeven, Boerma, & Meyboom-de, 1995; Coiera, 1996; Eysenbach & Diepgen, 1999), but those studies were not focused on the information behavior of lay people. The good news is that this trend has changed and more researchers are recognizing the need for understanding information use not only by health professionals but also by lay people outside the research setting as well (Evers et al., 2003; Shultz et al., 2003; Owens et al., 2010; Hong et al., 2012; Hu et al., 2012). This trend was also observed in Baker and Pettigrew's (1999) questions for future research where they addressed the need to understand more about what uses individuals make of consumer health information obtained from members of their social networks, the extent to which they actually acted on this information, and the impact that this information might have on their health situations. A recent example of this trend is the work of Stommel and Lamerichs's (2014) who looked into how advice from personal experience would change based on the format of delivery (direct advice, advice as a second story, if-then advice formulation).

In reviewing the literature, it was also important to touch on some of the aspects of stress, coping, and information avoidance theories. Whether or not health consumers are just collecting as much information as they can, as *monitors*[2] who tend to do to help decrease their stress in the presence of an aversive event, or find information to be a distracting behavior, such as in the case of *blunters*, who tend to avoid increasing their stress levels (Miller, 1987; Baker & Pettigrew, 1999; Baker, 2005). One point made by Baker's (2005) is that “blunters with chronic disease may want information, but they may seek it only when they know they can handle the stress the information may provoke.” Another point in terms of coping and avoidance

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[2] Monitors and blunters are characterized in terms of perceived threats. “Monitors are highly attentive and sensitized, and tend to amplify threats,” and “Blunters avoid and minimize the same threats.” (Miller, Summerton, & Brody, 1988)

In information science terms, *monitors* refers to those seeking information, and *blunters* refers to those doing information avoidance. (Miller, 1987) was made by Case's (2007) who indicated that “most of the time information is not avoided but rather simply not used” (p. 119) which is consistent with Dervin's (1983a) previous findings where she reported some people’s reasons for not using or for rejecting information was “it didn’t fit my circumstances,” or “I couldn’t make it work for me,” or “it arrived too late” (p. 170).

In another perspective, Kuhlthau's (2004) indicated that the classic triad of thoughts, actions, and feelings central to constructive processes is frequently overlooked in studies of information-seeking behavior. She also suggests that incorporating these dimensions is a necessary step to create a wider holistic view of information use as well. Similarly, Nahl's (2001) taxonomic approach provided insights into how to evaluate cognitive, affective, and behavioral information behaviors.

Thus, all these perspectives seem to suggest that consumers’ uses of information can vary extensively, starting with those who exercise information overload[3] to those to who practice information avoidance[4] (or simply do not use it). Hence, for this study, a combination of these

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[3] *Information overload* refers to the continual addition of information input increments over the human brain’s limited processing capacity, which eventually affect output and performance. (Miller, 1979)

[4] Information avoidance has been primarily studied in the context of health information, as it tends to be conceptualized as a coping mechanism for dealing with potentially unwanted information. (Manheim, 2014)

perspectives as well as results from Sweetland's (2000) study were used in the development of the information use categories for the data analysis. Findings from Sweetland's (2000) study about users' perceptions of the impact of information provided by a consumer health information service not only showed that users did seem to experience changes in their thoughts, feelings, and actions as a result of using information but also described some of those changes, and these were used to inspire some of the subcategories of the information use coding schemas defined for this study.

2.2. THE LITERATURE REVIEW PROCESS

In researching the literature there have been challenges because, even though this topic has a multidisciplinary nature, most of the current research is not yet truly multidisciplinary in the sense that researchers in the involved areas have tended to keep their research within their close-knit areas. In fact, Wilson's (1994) indicated that all disciplines are like that, including information science, but that nowhere was it more evident than in the field of user studies, a thought Dervin's (2003) well stated: “If we keep producing more of the same we'll make the pile higher and wider, but no deeper” (p. 4).

According to Wilson's (1994), research in health communication studies tends to be reported almost entirely in health sciences and so it is consequently rarely reviewed by information scientists. Thus, in order to avoid continuing with this inappropriate tendency, the researcher did multidisciplinary searches in several key journals and databases (as shown in Table 2.1) related to the three areas supporting this research.

Some of the descriptors used in the searches to locate relevant literature included: information-seeking behavior, online support groups, cancer support groups, self-help groups, online health support groups, virtual communities, information use and use behavior, information utilization, interactive health communications, and interactivity online, among others.

Table 2.1. List of Journals and Databases Searched for the Literature Review

Journals	**Databases**
Journal of the American Society for Information Science and Technology	PubMed
Journal of the American Medical Association	CINALH
Journal of American Medical Informatics Association	MedLine
Bulletin and Journal of the Medical Library Association	LISA
The New Review of Information Behavior Research	Inf. Science Abs.
Journal of Medical Internet Research	Library Literature
Internet Research Journal	PsycINFO
Social Science and Medicine	Diss. Abstracts

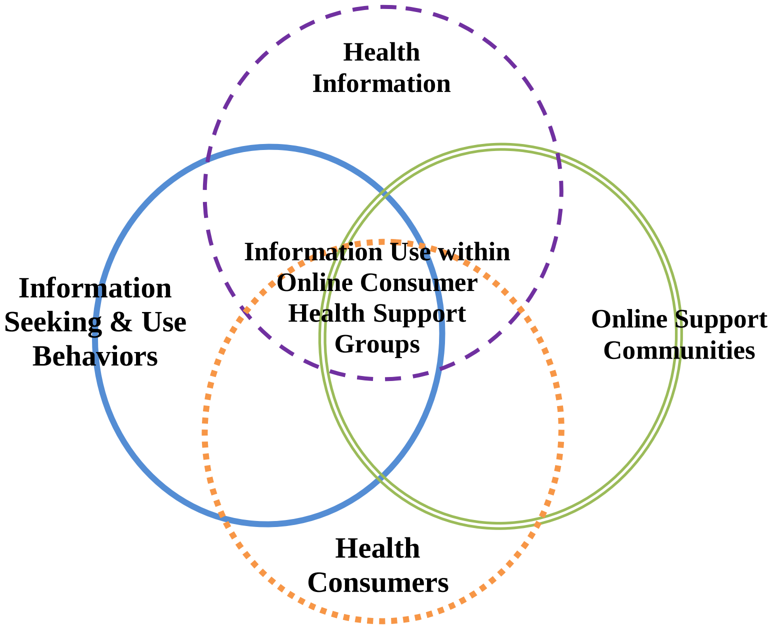

Figure 2.1 Research Areas Involved in Studying Information Use within OSGs

Based on all searches performed for the literature review, the research areas that seem to support the proposed research included: consumer health information, information-seeking and use behaviors, online support communities, and interactive health communication, and at the intersection of them we find this research about understanding information use within online consumer health support groups.

2.3. CHARACTERISTICS OF ONLINE HEALTH INFORMATION PARTICIPANTS

Members of online health support groups tend to be people that are diagnosed with a health condition, undiagnosed individuals with a health concern, or people caring for relatives with a condition (Kral, 2006).

According to Nupur's (2010), online health users are likely to be those dissatisfied that their needs are unmet by their provider and are, in turn, more likely to seek and use information from sources other than their physicians.

Other previous research studies (Caine, Burnham, Fisk, & Rogers, 2008) suggest that health consumers seem to be more willing to disclose to a computer than directly to their personal physician, especially when their responses may yield relevant feedback or addresses a critical information need (Kam & Chismar, 2002). More specifically, according to (Frost, Vermeulen, & Beekers, 2014), “Patients prefer sharing clinical information over daily life and identity information that can potentially compromise their anonymity.” Their research findings indicate that even though active participation in online communities has been linked to positive outcomes both online and offline, privacy concerns remains a key barrier to sharing information in online communities.

In general, men’s participation in online support groups seems to be less active than that of women, not because they have less need of support but because they may not feel as comfortable as women in asking about personal health information issues online (Eysenbach & Diepgen, 1999; Fox & Rainee, 2000; Klemm et al., 2003). Some researchers (Taylor, Falke, Shoptau, & Lichtman, 1986; Gray, Fitch, Davis, & Phillips, 1997; Coreil &

Behal, 1999; Klemm et al., 1999) point out that when men do ask for support, they tend to focus on gaining information and education about their disease as opposed to women who focus more on sharing their feelings and giving support to others (Harrison, Maguire, & Pitceathly, 1995; White & Dorman, 2001; Mo et al., 2009). Participants of online support groups also tend to have some difficulty with self-disclosure[5] (common when reporting socially sensitive personal health information).

One characteristic of online support groups users pointed out by several researchers is that participants tend to be married Caucasian women under 65, with a high degree of education, previous computer experience, and broadband access (Gustafson et al., 1993; Fernsler & Manchester, 1997; Calabretta, 2002; Peterson & Fretz, 2003; Fox, 2005).

Another feature of online information participants evidenced in the literature (Savolainen, 2001) that proved to be a major difficulty for this study was that most participants rarely gave feedback to those who provided them with help, which made them seem ungrateful. Savolainen's (2001) study suggests that “perhaps this might be evidence of a fragmentary, ‘cultural indifference’ characteristic of cyberspace where information seekers and information providers remain strangers to each

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[5] *Self-disclosure* means “revealing one’s true self to some degree” according to (Kam & Chismar, 2002)

other” (p. 86). One way to verify Savolainen's (2001) beliefs about cultural indifference in CMC would be by directly asking participants on online support groups their reasons for not giving any feedback to those who provided them with answers to their questions.

According to Rice's (2006), more frequent online health seekers were more likely to: engage in dialogic online interaction, believe the information they saw online, use the internet to diagnose or treat a medical condition on their own without consulting a doctor, ask their physicians new questions, say the Internet had improved the way they take care of themselves, and change the way they manage their chronic condition. Other researchers (Barak, Boniel-Nissim, & Suler, 2008) have also reported that “it is well known that people tend to say and do things in cyberspace that they ordinarily would not say or do in the face-to-face world” (p. 1870).

2.4. HOW IS INFORMATION USE BEING ADDRESSED IN THE LITERATURE?

The evaluation of how information use is described in the literature was researched from the perspective of information and use, and from the perspective of the health information itself, both of which are the major disciplinary areas involved in this research. The research also looked into the phenomenon using a consumer’s perspective and, more recently, from the perspective of information literacy, which is an emergent area.

2.4.1. THE INFORMATION SEEKING AND USE PERSPECTIVE

To get a better understanding of information use within online sources such as support groups, it is important to first understand how research in this area began and how it has changed or evolved over the years.

According to (Case, 2014), “Serious research on information seeking and use began in the late 1930s, when a few investigators began to look more in depth at what people did with documents,” but he also pointed out that this kind of investigation didn’t become mainstream until the 1990s.

Looking back into previous research, we found the work of Bertram Brookes, one the founders of information science, who said that the major task of information science was to “put flesh on its bones by analyzing examples of knowledge structures and by observing how they respond to information received” (Brookes, 1975, p. 117). Thus, by analyzing how bulletin board participants react to information received, this research is on the right track to add to the understanding of the interactions between people and information.

Continuing the look back, the work of Dervin and Nilan's (1986) described that before 1978, most of information behavior research emphasized users’ adaptation to information systems outputs rather than emphasizing users as the drivers of the systems.

In 1986, when Robert Taylor was trying to understand how systems could be improved by looking into information use environments, he realized that as Palmquist's (2009) puts it, “Only the potential for value was carried by the information and that it was in the head of the user or in the use of the information that a message had value” (p. 355). Then in Taylor's (1991) later work, he proposed his taxonomy of eight classes of information uses as a set of elements that affect the flow and use of information messages. The problem with these classes, as Bartlett and Toms's (2005) research study points out, was that they were not developed from reports or discussion of actual uses but instead from expressions of perceived needs.

Thus, since the users were not the main focus of the information-seeking and use research in the past, it seems justifiable to believe Dervin, Jacobson and Nilan's (1982a) statement that “the lack of emphasis on individuality has accounted for the relative lack of emphasis on information use in the health communication literature” (p. 21). Then follows Dervin and Nilan's (1986) sense-making theory perspective which describes that individuals make new sense with information from the environment by building a bridge over a gap, and part of that bridge, as Spink and Cole's (2006) suggest, is “information about the how the information will be used or is been used” (p. 27) causing a cognitive, affective, or behavioral transformation (Todd, 1999b).

This lack of emphasis is also present within information science research as evidenced by the fact that the concept of information use has not only been difficult to capture, vaguely or inconsistently defined, or not defined at all (Savolainen, 2009), but it has also been conceptualized in several different ways by different researchers as reported by Kari's (2010) study, including: as information practices, as information search, as information processing, as knowledge construction, as information production, as information application, and as effects of information. In fact, according to Todd's (1999a) and Raya's (2012) studies, other similar, related terms which include information utilization, knowledge use, and knowledge utilization, are often used interchangeably. Regardless of the inconsistencies defining the term, Todd's (1999b) research indicates that even though any definition of information use is directly tied to how one defines information itself, the literature generally conveys that "information use is about people doing something with information they have sought and gathered themselves or provided by someone else" (p. 852).

From the wider perspective, information use research is one of the three core elements of information behavior, the others being information needs and information seeking (Wilson, 1999). The last two elements have been well studied, but information use has always received less attention. The information-seeking literature also describes that there are two predominant perspectives with respect to information use and utilization. One of these perspectives refers to information use in the organizational systems context; the other uses a more holistic view based on the sense-making perspective in which the notions of cognitive, behavioral, and affective change are central concepts to the definition of information use and utilization (Todd, 1999b). This second perspective is the one used by this research in order to gain some understanding about what information from online discussion boards is used and how from the point of view of the health consumers themselves.

One of the investigations most aligned with this present study, in terms of the interest in information use, is Dervin, Nilan and Jacobson's (1982b) descriptive study about the human side of information within a health context. They looked at how patients saw their most recent visit to doctors, and studied how the information patients obtained helped or did not help them. Dervin's (1992) study called these helps *utilities,* and they actually represented the uses variable in her study where use was defined as “ways in which people put answers to questions to work” (p.11).

Thus, for this research, Dervin et al.’s (1982b) content analytic scheme for tapping the nature of utilities was used as the starting point for the development of a coding schema to categorize information use instances from online health support groups. In Dervin et al.'s (1982b) approach, they talked about:

> Obtaining time-space bound situational gap measures by asking their respondents if they had any questions at that point and they also talked about obtaining measures of information use by asking respondents how the information would have or actually did help them. (p. 811)

Rakowski's (1990) research looked at information seeking from two indices (information positive and information negative) and found that having information (in other words, documents, videos, or pictures with data or facts) did not guarantee that behavior change would occur (this was similarly expressed by Wilson and Walsh's (1996) in terms of information processing and use) but being an active information seeker, those with a 'positive' information index[6], would make a citizen more likely to engage in personally conducted health activities, such as breast self-examination, tooth-flossing, regular exercise, limits on exposure to sunlight, etc., than those with a 'negative' information index.

In 2001, Pettigrew, Raya and Bruce's (2001) suggested that since the 1990s, another trend had emerged in the field that emphasized the contextual interplay of cognitive, social, cultural, organizational, affective,

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[6] *Information index* is a summary index derived from perceived positive (pros) and perceived negative (cons) features of the target behavior as defined by (Rakowski *et al.* , 1997)

and linguistic factors of information behavior. Around the same time, Savolainen's (2001) research concluded that "ideally information seeking and provision occurring in online support groups should be based on a dialogue" (p. 87). It could be said, then, that for information use to occur, a complete dialogue-feedback exchange between the information seeker and respondents should happen. In that way, others in similar situations could potentially also use the information to solve their concerns.

Another perspective about information use is that of Choo's (2002) where he suggests that information use is "a dynamic, interactive social process of inquiry that may result in the making of meaning or the making of decisions" (p. 58), which, as Bartlett and Toms's (2005) indicate, even though this perspective is from the view of organizational decision making, some aspects can be applicable to individual decision making. As an example of 'making meaning' we found Kuhlthau's (1991) work where she points out that "evidence of the transformation of information into meaning is present in the products or presentations in which users share their new knowledge with others" (p. 361), as can be the case within online support groups when peers report their experiences and how they have used information received to other peers.

Research such as that of Wagner, Baker, Bundorf and Singer's (2004) looked into the extent to which information from the Internet had effects on people improving their understanding of their condition, their treatments, the way they ate, or led them to seek different doctors. They found that people with chronic conditions made only moderate use of online health information, and that the "self-reported effects of treatment or providers were small but noteworthy" (Wagner et al., 2004, p. 1). This might have been a consequence of their choice to oversample veterans and older adults.

One of Chen's (2014) recent research studies looked into information use over time from the perspective of illness coherence[7], such as whether various types of information use were linked with personal control at various stages of an illness. They only considered five types of information use (to better understand one's illness, to talk with one's physician or healthcare provider, to select a new medication, to select a new treatment, and to cope with one's illness) which is a limited set and doesn't include the cognitive, affective, and behavioral aspects of information use that this research focuses on.

In contrast, Savolainen's (2015) more recent research expanded on the relationship between cognitive and affective factors by comparing Kuhlthau's (1991) information search process model and Nahl's (2007a)

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[7] *Illness coherence* refers to the degree to which patients understand or comprehend their illnesses, as defined by (Moss-Morris *et al.* , 2002)

social-biological information technology, but it did not include the behavioral actions that are an important part of this research.

This research agrees with that general conceptualization of information use but defines the “doing something” as the cognitive, affective, and behavioral steps taken by people to try solve their problem situation.

Other information-seeking and use studies of online consumer behavior, such as that of Roscoe, Grebitus, O'Brian, Johnson and Kula's (2015), reported in their findings how decision making can be affected by information found in some sites even if the information is not necessarily free of publishers’ influence. This point of view about the effects of information on decision making is another way of talking about information use, since there cannot be decision making without “mover-created effects” (Dervin, 1983b). Similarly, other researchers (Van Deusen & Van Dijk, 2009; Darley, Blankson, & Luethge, 2010; Monchaux, Amadieu, Chevalier, & Marine, 2015) suggest that publishers’ influence together with the fact that many individuals lack strong digital information literacy skills can lead to flawed searches with biased, inappropriate decisions being made, and hence, reduced satisfaction.

Similar decision-making studies (Entman, Matthes, & Pellicano, 2009; Boukes, Boomgaarden, Moorman, & De Veese, 2015; Roscoe et al., 2015) have concluded that online persuasion[8] is not limited to just commercial sites but also includes informational sites such as Wikipedia, and news sites such as NYTimes.com, either of which can present information in different ways to attempt to sway readers understanding, or to make readers believe they should use that information. It is important to point out, as suggested by (Perloff, 2003), that “people persuade themselves to change attitudes or behavior” (p. 2) as a result of the intentional arguments of the communicators. Hence, persuasion could be seen as a kind of information use when the persuasion is effective in influencing consumer choice (in other words, the receiver of the information changes attitudes or behaviors in line with the message sent by the communicator doing the persuasion) (Roscoe et al., 2015). If no behavioral or attitudinal change occurs, then the persuasive information was not used. Thus, when a participant is persuaded into doing what other peers suggest, that implies he or she had used the information received.

The last and most current shift in the understanding of information use is, as Case's (2014) suggests, focused on the chunk, where attention is turned to units of information smaller than documents and which originated from different sources including not just the document but also conversations, mass media, the web, and social media. This type of focus on

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[88] Persuasion can be defined as a conscious attempt by one individual to change the attitudes, beliefs, or behavior of another individual or group of individuals through the transmission of some message. (Perloff, 2003)

smaller chunks of information is precisely where this research about understanding information use in online SGs falls.

Even though several researchers have proposed slightly different points of view about information use, work in this area still seems to be an understudied aspect of information behavior, possibly because it is not easy to study outcomes of information or to determine what exactly qualifies as information. This means that there are more aspects remaining to be discovered or better explained.

2.4.2. THE HEALTH INFORMATION PERSPECTIVE

Looking into how health consumers use information from online support groups represented a good way to study information use since, according to (Sundar et al., 2011), “A principal attribute of online health technologies is that their content is intrinsically related to user behavior, and both the design and effectiveness of health information strategies depend heavily on a clear understanding of users and their use patterns” (p. 189).

The initial research work of Johnson and Meischke's (1991) has been on the types of information that cancer patients might seek (for example, factual cognitive information or affective coping information). In later work, Johnson and Meischke's (1993) study highlighted that “individual information seeking has become a critical element in determining health behaviors” (p. 343) and proposed a model of information seeking, but little research has focused on how these health consumers make use of information they received from informal online sources.

Looking back a few decades, as Sudau, Friede, Koschack, Makedonski and Himmel's (2014) points out, we have seen a strong shift from a paternalistic doctor-patient relationship, where the health professional felt that patients were unable to cope with bad news and should therefore be kept ignorant of many details of their illness” (McMullan, 2006, p. 26), toward an active, self-managing, and autonomous patient that participates in online forum communities trying to find answers from others, including peers. One motivation for this shift in not only the amount of health information and support freely available online, but also the fact that “doctors do not usually ask their patients what they think or feel about a diagnosis or treatment, hence reinforcing patients’ reluctance to disclose their psychological concerns” (Lee & Hawkins, 2010, p. 156).

Other research carried out in the consumer health information area related to human information behavior has been directed toward exploring the efficacy of communication channels used by people at different stages of health, toward investigating people’s predisposition to explore or reject information (Wilson, 2000), or, in terms of the degree of utilization of research findings by practitioners, toward learning about health consumers' preferred sources of information (Bond, 2000).

For some researchers within the consumer health information area (Bedsworth & Molen, 1982; Van Der Molen, 1999; Weis, 2003), information use is seen as a coping strategy, where direct, self-regulating actions at the cognitive, affective, or behavioral levels occur to deal with health threads. This view of information use from the health information perspective can be traced back to the 1980s with the transactional model of stress and coping proposed by Folkman and Lazarus's (1980) study in which they stated that the term *coping processes* refer to what the person actually thinks and does in a particular encounter.

In another view, Wagner and Hibbard's (2001) study suggests that poor health status, the presence of a chronic illness, and having children are indicators of greater information use because people with these conditions would be facing health-related uncertainties and have the potential to benefit immediately from using it. Wagner, Hu and Hibbard's (2001) also revealed that incentives would likely need to be created in order to motivate healthy individuals to learn about prevention and healthy behaviors and that "the increased use of health information was, for the most part, due to the increased availability of "free information" rather than to an advertising effect" (p. 595).

The review of the literature also revealed that both patients and consumers deal with information differently at different stages so their reactions toward information gathered are also expected to vary (Nicholas, Jamali, Huntington, & Williams, 2007; Miller, 2010; Jayanthi, 2015). This situation could be explained through Miller's behavioral theory, which indicates that there are those that seek information (monitors) when they feel threatened with an aversive event because that helps to decrease their stress, and others who avoid information about stressful events (blunters) because information increases their stress level (Baker, 2005; Wilson, 2006). The problem of applying Miller's theory in this research is that, as pointed out by Baker's (2005), it doesn't consider the information-seeking behavior of people with chronic diseases where the distinction between monitors and blunters tends to blur over time, which is the case being studied here. This blurred distinction is evident in Sweetland's (2000) findings that even people who have been chronically ill for a long time were well informed and gained new knowledge and reassurance, contrasting, as she suggests, with others who thought that health information may have little effect on the knowledge of the chronically ill.

Another theory that could help to explain health consumer's behavior in online support groups is Granovetter's (1982) theory of the spread of information in social networks called the "Strength of Weak Ties" (SWT).

This theory suggests that strangers could offer an advantage over friends and colleagues in obtaining useful information because weak ties comprise more numerous heterogeneously diverse helpers than strong ties do, so they are able to provide multiple perspectives or skills on stressful situations that a close-knit friend or family may not be able to provide (Granovetter, 1982; Savolainen, 2001; Goldsmsith & Albrecht, 2011; Wright, Johnson, Bernard, & Averbeck, 2011). Also, as pointed out by Wright and Bell's (2003), weak ties provide members with an opportunity to talk to other participants about detailed or potentially offensive aspects of diseases or conditions that would be difficult to reveal to others who are close ties because close ties tend to move in the same circles and so the information seekers receive information that overlaps with what they already know. According to Colineau and Paris's (2010), weak ties can also be a source of emotional support. Because of their emotional distance, they can provide more objective feedback. In terms of this research, the SWT theory helped to understand why participants of online support groups are more willing to discuss and disclose their health issues with strangers. The SWT can also help to explain the increased popularity of such groups for health-related issues in spite that the reliability of the information received could be very difficult to determine, misleading, or confusing (Savolainen, 2001).

The increasingly widespread use of health information has given rise to concerns about health literacy and the ways people process and use health information (Baker, 2006). Thus, this point of view is important not only because information from the Internet can be of limited value to people with low eHealth literacy[9] (Hu et al., 2012), but also because, as suggested by (Souden & Rubenstein, 2010):

> Information behavior perspectives on information use have the potential to broaden notions of health literacy beyond the point of information delivery, considering how information is actually used and made valuable in people's lives and made sense in the context of their own experiences. (p. 2)

This is why looking into people's experiences using information for learning about their health (Bruce & Hughes, 2010; Li, Orrange, Kravitz, & Bell, 2014)—which is related to this research's focus—can provide a means for the design of better ways to deliver health information as well as to create environments that support people's desires for effective health decision making and positive action (Yates et al., 2012).

Current research initiatives, as described by Souden and Rubenstein's (2010), emphasize core information literacy skills (readability, clarity in communication, appropriate venting online), nevertheless, "These measures

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[9] eHealth literacy has been defined as 'he ability to seek, find, understand , appraise and apply health information from electronic sources for the purpose of addressing or solving a health problem (Norman & Skinner, 2006).

do not address the complicated ways in which people interact with and use information when making decisions about their health” (p. 2).

Lastly, it is important to note that health consumers’ behavior seems to be comparable with consumers’ purchasing decisions in terms of the effects of peers in decision making. For example, both health consumers and buyers indicate that online interaction facilitates getting different information, including factual or first-hand experiences, from a broad range of other people, which Chatterjee's (2001) describes as consumers having advantages of scale in their purchase-oriented decision making from reviewing other consumers’ evaluations online. Also, in both groups, the strength of ties are weak because they tend to trust and use suggestions from strangers, which Chatterjee's (2001) also supports: “In the online medium however, the “tie strength” is always very weak” (p. 2).

2.4.3. THE CONSUMER’S PERSPECTIVE

A very high volume of nonhealth, online peer-to-peer information use is related to product reviews by consumers. Research specifically related to consumers has been published mostly in journals related to marketing and advertising, and generally, they refer to consumers in the sense of buyers and shoppers, which, as pointed out by Case's (2007) study, leads to the wrong assumption that consumer research does not include basic human behavior.

Nevertheless, there are other areas where some research about consumers, specifically health consumers, is emerging and those are related to health research and technology assessment in health care, as evidenced by Wagner and Hibbard's (2001) publication that highlights the importance of "understanding more about who uses consumer health information in order to develop and promote health interventions or health information systems" (p. 591). Case's (2007) study also pointed out that consumer research is of interest in "the importance of context in understanding humans reactions to things and messages" (p. 334). This is in line with the research proposed here about how health consumers use information exchanged in online discussion boards.

Many people actively participate in online consumer communities, which, according to (Bickart & Schindler, 2001; Mangold & Faulds, 2009), affect their purchase decisions as well as their relationship with the companies that sell the products. These online consumer communities, where customers' ability to communicate with one another is magnified, allows them to limit the amount of control that companies have over the content and dissemination of information. More specifically, consumers in these forums believe that the information shared in them is more trustworthy and relevant, and reflects typical product performance better than marketer-generated information because fellow consumers are perceived as having no vested interest in the product and no intentions to manipulate the reader (Bickart and Schindler's (2001).

Other researchers, such as (Pan & Chiou, 2011; Hajli, 2014), point out that social media facilitates the social interaction of consumers and exchange of experiences, leading to increased trust and intention to buy. These researchers also refer to the sharing of experiences as an electronic word-of-mouth that helps consumers in their purchasing decisions, which parallels health consumers' sharing of information, receiving support from online peers, and experiencing behavioral changes as a consequence. Hajli's (2014) also suggests that “social factors facilitated through social media develop a supportive climate which in turn attracts many more individuals to come online to take part in social interactions” (p. 400), which in turn influences consumers' attitudes towards a product or service. Researchers also suggest that more research in this area is still needed to gain a better understanding of the persuasive influence of OSGs.

More recently, a study by Fiksdal et al. (2014) exploring consumer perspectives on health information searching, reported that their participants' experiences about how they used the information they found through Internet searches included practical reasons related to time and money, as well as a means to enhance a clinical visit.

Another interesting way of looking at information use is from the view of consumers' literature and how users of eWOM (electronic word-of-mouth) evaluate its usefulness (Park & Lee, 2009) and its persuasiveness value (Zhang, Craciun, & Shin, 2010), since, as they put it, "The lack of social cues forces consumers to evaluate eWOM persuasiveness solely based on content characteristics" (Zhang et al., 2010, p. 1). Their study has parallels to this study, evaluating online information use solely on the content of threads. In their study, Zhang et al. (2010) also talked about the way consumer-reviews affect consumers depend on their regulatory foci[10]. They argued that "regulatory foci motivate consumers to give different weights to positively vs. negatively valenced messages" (p. 2). Using a similar approach in this research could possibly explain why consumers choose to act upon information exchanged (information use) one way as opposed to another way depending on the message received.

2.5. OVERVIEW OF THE ONLINE SUPPORT GROUPS LITERATURE

The following subsections provide an overview of: reasons why consumers participate in online support groups, current research on this form of online interaction, advantages and disadvantages of online support

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[10] Regulatory foci refers to people two different modes of self-regulation: promotion and prevention where consumers with promotion foci are more concerned with advancement and achievement through product consumption, and consumers with prevention foci are more concerned with the avoidance of negative outcomes. (Zhang, Craciun, & Shin, 2010)

groups as well as how they differ from newer social media technologies and traditional face-to-face support groups.

2.5.1. WHY DO HEALTH CONSUMERS GO TO ONLINE SUPPORT GROUPS?

Several explanations about health consumers’ participation in face-to-face support groups discussed in previous research (Evans & Clarke, 1983; Buckland, 1994; Levitt, Lamb, & Voss, 1996) are still valid today in explaining people’s need to go online for support. These explanations include that medical professionals are often hesitant to offer advice unless it’s requested; health consumers consider their questions inappropriate or are embarrassed to ask them face to face; visits to physicians are insufficient to meet the informational needs of patients and their families, people perceive that there is a lack of information or explanations about treatments from medical practitioners (Malik & Coulson, 2008a), or patients just want to know more about their health condition (Wicks et al., 2010).

Another reason, as described by Barak et al.’s (2008) study, is that “these groups based themselves on the simple premise that people who share similar difficulties, misery, pain, disease, condition, or distress may both understand one another better than those who do not and offer mutual emotional and pragmatic support” (p. 2). In fact, according to Fox's (2011) about 18% of internet users say they have gone online to find others who might have health concerns similar to theirs. Some other consumers, like men in the infertility groups, used them because they feel they can vent or express their fears of disappointment more openly without upsetting their partners (Malik & Coulson, 2008b).

Even though evidence of the impact of participation in online communities is still limited (Wicks et al., 2010), understanding online discussion forums is important because, as suggested by Ginossar's (2011), support groups have the potential to impact not only the degree to which patients and their family members feel emotionally supported by others with similar conditions, but also because they learn about the nature and efficacy of their treatment decisions. The difficulty that patients and consumers have with managing complex and chronic diseases have motivated patient organizations, providers, and nonprofit organizations to create a number of online communities where patients/consumers can discuss their health concerns and exchange information. Also, Nupur's (2010) study supports the notion that online health support for people with health issues, especially those with chronic conditions, can be critical, and there is a need to find ways to assess the effects of online support on health.

Another motivator for going to OSGs is that people today, as suggested by Johnson and Ambrose's (2006), tend to form more loose ties, where their multifaceted health needs can be addressed in ways the traditional health care infrastructure has been unable to, and this includes that “information on the internet can often be more timely than that available through other forms of media” (Leimeister & Kremar, 2005, p. 2).

Other reasons included geographically related limitations,[11] physical limitations related to their condition[12], and because people have a need to seek out peers who can help them comprehend their condition-related,[13] daily living issues, especially when their situation is uncommon and their social network doesn’t contain any people with similar conditions and experience (McKenzie, 2003). Some health consumers also go online because they like the greater sense of anonymity that online support groups seem to provide, because online support groups offer an alternative to professional care that empowers them, because they want to find out what questions to ask their physicians, or just because, for instance, most cancer patients want to reassure themselves they have all the information that there is even if they don’t use it.

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[11] *Geographically related limitations* refers to the lack of or limited availability of health information resources for those consumers that live in rural areas, or in parts of the world where there is less developed research on a particular condition, or when their conditions is uncommon.

[12] These conditions are chronic, debilitating, stigmatizing, uncommon, or poorly understood and inhibit them from attending traditional face-to-face support group meetings.

[13] Condition-related issues include: understanding of treatment, understanding how therapies feel, understanding how the condition affects marriage, and family, coping strategies, etc.

Other times, health consumers go to online support groups because information about alternative therapies is not necessarily supported by the medical community (Alexander, Peterson, & Hollingshead, 2003). As indicated by Bauerle Bass's (2003), patients reported feeling empowered by the information because it allowed them to ask their doctors well-informed questions.

Even though interactive health communications contexts, such us online support groups, as reported by Khoo's (2014), are “studied more than other kinds of forums, and have been shown to serve a useful function in helping patients with chronic and severe diseases to manage their condition” (p. 30), their research stills points out that the actual use of information is more difficult to study, since it requires some level of inference and analysis of a series of subsequent posts by the same user in a thread, which is precisely the data and analysis process that this research followed. Additionally, the importance of the work presented here is supported by recent research studies (Mo & Coulson, 2013; Oh, Ozkaya, & LaRose, 2014) that report a positive association between well-being and support received from using online groups and communities.

2.5.2. RESEARCH ON ONLINE HEALTH SUPPORT GROUPS

The notion of support groups is nothing new. They are a good example of a virtual community and as such, they are formed by “a group of people that share a common interest about a specific topic, and communicate frequently for some duration in an organized way over the internet through a common mechanism” (Ridings, Gefen, & Arinze, 2002, p. 273).

Even though, as Klemm et al.’s (2003) study indicates, traditional face-to-face groups have been around since the 1900s, and the online versions have only been around since the early 1980s, throughout the years, this notion of the importance and need for support groups to help people cope and deal with their health concerns has continued. Now, with the upsurge of the Internet and popularization of peer-to-peer communications, what has changed are the synchronous and asynchronous ways (chat rooms, listservs, newsgroups, and bulletin boards) in which peer support groups can be implemented. Results reported by Fox and Duggan's (2013) work indicate that of the 72% of people who searched for health information on the web in 2012, 26% indicated that they have read about or watched a video about someone else’s experience regarding health or medical issues.

Despite several previous and some recent empirical studies analyzing different aspects of online health information behaviors of patients, caregivers, and consumers that express a need for group relationships with other people with the same health concerns (Coulson et al., 2007; Malik & Coulson, 2008a; Mo et al., 2009; Van Uden-Kraan et al., 2009; Malik & Coulson, 2010; Fox, 2011; Hong et al., 2012; Hu et al., 2012; Oprescu, Campo, Lowe, Andsager, & Morcuende, 2013; Biyani et al., 2014; Chung, 2014), researchers continue to point out that work in this area is still lacking.

According to Klemm et al.’s (1999) research work, there were only ten studies on Internet-based cancer support groups, but none focused specifically on how the information from bulletin boards is actually used by participants, which is the focus of this research. Among these studies we found the work of McTavish et al. (1995) and Weinberg, Schmale, Ukan and Wessel's (1995), which focus on computer use and reactions to computer-based support systems. Weinberg, Schmale, Uken and Wessel's (1996) study paid attention to the therapeutic factors and time required to use a computer, extent of use, and types of messages in a private computer-mediated support group. Fernsler and Manchester's (1997) study looked at computer-based online cancer support networks but in terms of reasons for participating in them, helpfulness, and factors affecting their use. Sharf (1997) did a participant observation and discourse analysis study to examine the interactions among participants of a breast cancer listserv. Klemm and Hardie (2002) performed content analysis of messages posted to three different cancer support groups (breast, prostate, and colorectal) where she identified general themes discussed in the board and major gender differences in terms of the categories of the responses. In their studies, Klemm et al. (1998; 1999) compared depression rates between people in face-to-face and Internet-based support groups.

Almost all of the studies cited, except Klemm et al.'s (2003) work, used small convenience samples, which was not the case in this research study. Also, only four of these studies used support groups from the web as opposed to the other six that used private computer-mediated systems designed by the researchers themselves.

Klemm et al.'s (2003) study also pointed out some of the gender differences found by other researchers in terms of the purposes for which each gender utilizes support group meetings and the pattern of participation (participation in face-to-face meetings differs from that in online support groups). There was one important thing in common in all the studies reviewed by Klemm et al. (2003): they all concluded that online cancer support groups helped people cope more effectively with their disease, which, again, emphasizes the importance of this study. In terms of gender, this study will also look at whether gender makes any difference in terms of how the information is used by the participants of the online support groups being studied.

Other studies regarding Internet-mediated information include those cited by (CyberDialogue, 2000); Nicholas, Huntington, Williams and

Blackburn's (2001) where researchers indicated that information seekers advised family members or friends to take some health-related actions (see a doctor, change eating or exercise habits, check a website, or join an illness support group). Others studied whether online peer support groups provided any benefit to those suffering from kidney disease or how coping with grief was enhanced by receiving support and having contact with peers. Johnson and Ambrose's (2006) research on patients' 'neo-tribes'[14] support the notion that online communities helped to satisfy fundamental emotional and cognitive needs of patients. Likewise, Van Uden-Kraan and Drossaert's (2008) study investigated which empowering processes, according to their participants, take place in online support groups. Their resulting list of empowering processes is in line with part of the information uses schema described in this study.

One more reason for studying online forums as suggested by Chen's (2012) study is that "it could facilitate an increased understanding of how differences in the nature of health conditions might lead to differences in the types of informational and emotional support exchanges seen in online discussion forums" (p. 251).

In spite of the previous studies, still, as Malik and Coulson's (2010) report states, "The extent to which online support groups are effective in

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[14] A neo-tribe is another work for online communities. (Johnson & Ambrose, 2006)

providing the helping techniques known to be beneficial in traditional group interactions remains unclear" (p. 315). For that reason, they concluded there is still a clear need for further investigating outcomes associated with online support use.

2.5.3. ADVANTAGES AND DISADVANTAGES OF ONLINE SUPPORT GROUPS

Some common characteristics of online support groups pointed out by Culver, Gerr and Frumkin's (1997) include their self-governance, nonprofit status, and democratic ideology. Another important characteristics of online support group communities is that, as opposed to a mailing list where members passively receive information, members here must actively choose to go to the community to review messages (Ridings & Gefen, 2004). Additionally, the whole conversation is preserved.

In terms of the advantages of online support groups, some are the same as those that face-to-face support groups provide to their participants plus some other benefits that are unique to this online environment. These advantages include:

- Online support groups are able to transcend geographical and temporal constraints by providing convenient, support and information for anyone who wants it, 24 hours a day, 7 days a week, in any location. This is especially beneficial for people with disabilities or who feel debilitated by their condition and people living in rural areas or where there are currently no other forms of support available (Klemm et al., 1999; White & Dorman, 2000; Cline & Haynes, 2001; Han & Belcher, 2001; White & Dorman, 2001; Chung, 2013).

- Individuals are better able to find and bond with an increased number of other participants experiencing similar conditions and hence able to compare treatments regiments and share practical advice that better fits their needs (Sharf, 1997; Cline & Haynes, 2001; Calabretta, 2002; Johnson & Ambrose, 2006). Similarly, public health research indicates people with same cultural background benefit from online health interactions because cultural values affect behavior (cited in Grimes, Landry, & Grinter, 2010).

- Participants can have access to information on sensitive or embarrassing topics without the feeling of disconfirmation or stigmatization that can occur in face-to-face interactions (Cline & Haynes, 2001; White & Dorman, 2001; Malik & Coulson, 2008b; Ballantine & Stephenson, 2011; Wright & Rains, 2013; Rains, 2014).

- Because of the perceived anonymity and perceived social distance from other participants, OSGs facilitate increased perceptions of reduced risk in terms of self-disclosure, so individuals are more willing to disclose personal information and experiences to other members of the group (Eysenbach, 2003; Tichon & Shapiro, 2003; Weisgerber, 2004; Li, Feng, Li, & Tan, 2015; Huang, 2016).

- Distracting signs of physical appearance, facial and body expressions, gender, and weight are eliminated, so postings are judged based on the quality of the contribution without being affected by any appearance attribute (Davison et al., 2000; Han & Belcher, 2001; Martin & Youngren, 2002).

- The format of these groups, where each posting can be read by all members, gives participants access to multiple sources of information and diverse viewpoints about issues (Wright & Bell, 2003; Colineau & Paris, 2010). These multiple perspectives facilitate participants' ability to find others with their preferred coping style (Wright & Rains, 2013).

- Online support groups also support connectivity among people from different cultural and socioeconomic groups (Coulson, 2005).

- Most participants describe information provided in online forums as "being understandable" because it is formulated in their "own language" (Van Uden-Kraan & Drossaert, 2008).

Information exchange and support in an online discussion environment doesn’t come without any drawbacks. Some of them include:

- Participants need to own a computer with broadband access and communication software, or at least be able to have Internet access from a public place (Madara, 1997; White & Dorman, 2000, 2001; Klemm et al., 2003).

- Not every patient or consumer who could benefit from participation in these types of communities has the means to access one or the skills needed to use the technology (Johnson & Ambrose, 2006).

- There are no current standards to stop the dissemination of false or misleading information other than members of the groups themselves who might point them out but not always in a timely manner (King & Moreggi, 1998; Johnson & Ambrose, 2006). In the same way, members of the support groups themselves can be culpable of disseminating misleading information simply because much of their guidance is based on personal experience (Culver et al., 1997; Winzelberg, 1997; Cotten & Gupta, 2004). In contrast, Van Uden-Kraan et al.’s (2008) study suggest that fears about possible exposure to dangerous information may be unfounded.

- For the health consumers, it is often difficult to differentiate between what is accurate and what is incorrect, including possible spam or off-topic remarks which can come with a considerable amount of noise and varying quality (White & Dorman, 2001; Epstein, Rosenberg, Venet Grant, & Hemenway, 2002; Eysenbach, 2003; Wright et al., 2011).

- The presence of antisocial hostile behaviors, such as flaming, trolling, or spamming, can be difficult to avoid and control (Madara, 1997; Winzelberg, 1997; Burnett, 2000; Eysenbach, 2003).

- Determining if participants who claim to have the condition actually have it is almost impossible since the medium anonymity can facilitate deceptive practices (Madara, 1997; Alexander et al., 2003; Wright et al., 2011).

- Participants may sometimes feel so powerfully linked to other online members that they might replace their doctor's advice with suggestions from their online peers, which will not always be appropriate (Rosenberg & Epstein, 2001).

- Some online communities have a low response rate or lack of reciprocity that stops some members from contributing (Fan, Wu, & Chiang, 2009).

2.5.4. COMPARISON WITH NEWER SOCIAL MEDIA TECHNOLOGIES

This study focused on online support groups as the medium used by health consumers to share information with peers and reports how information and support received was used, but it is important to mention that other media have arisen more recently to share and discuss health information among patients and consumers. These other media (Facebook, Twitter, YouTube, personal blogs, and PatientsLikeMe) vary in the degree of privacy, amount of information that can be disclosed at a time, and whether the patient/consumer needs to be a registered member to be able to have access to that information. They offer some similar advantages to online support groups such as the wider reach to people with similar issues, or access to otherwise unavailable peer experiences as well as information and support.

One differentiating advantage of online support groups is the relative anonymity and privacy they provide to participants. In the case of social media such as Facebook or Twitter, achieving anonymity and privacy is more challenging because of the increased visibility of user profiles and personal networks with a greater audience (Bender, Jimenez-Marroquin, &

Jadad, 2011). Other differentiating features include that most of the social networking data comes from ‘individual gatekeeping’ (Hu & Sundar, 2010); questions and related answers are not stored and displayed in the organized way online support groups use and they have a more general purpose than online support groups and sites such as PatientsLikeMe where the information comes from ‘collective gatekeeping’ (Hu & Sundar, 2010), and it is stored and displayed in threads.

Another issue that argues against using social media for health support is, as indicated by Munson et al. ’s (2013) study, the gap between what users know about social media systems as it pertains to health, and how they actually work and what they do or don’t do. In addition, since people typically use Facebook as a medium to maintain previously known relationships, then when they want to report their health status, they can experience a conflict of interest because, as reported by Newman et al.’s (2011) study, people always want to present a favorable and positive view of themselves to their friends or family, even when that might not be what their actual status is (Walther, 1992).

Similarly, as Lee and Hawkins's (2010) study described, cancer patients are concerned that open discussion of their feelings about their illness may upset or hurt their family or, in other cases, family may not allow the patient to express emotional distress over the illness. Participation in online support groups, on the other hand, seems to enhance patients' self-efficacy level (Lee, Hwang, Hawkins, & Pingree, 2008).

Looking into self-reported questions asked on Facebook and through Twitter, (Sharoda, Hong, & Chi, 2011) found that most participants asked about recommendations and opinions related to technology and entertainment, and that participants felt uncomfortable asking questions about health, religion, and dating because they were too personal. In the case of Twitter, De Choudhury, Morris and White's (2014) more recent study shows that it has increasingly been used for health-oriented question-and-answer tasks. One problem found with Twitter was that the personal and health-related questions had a very low response rate of feedback.

PatientsLikeMe is an online discussion-oriented community built to enable the exchange of health information and support between patients about their life-changing health issues (Frost & Massagli, 2008; Wicks et al., 2010). The site provides "customized disease-specific outcome and visualization tools to health patients understand and share information about their condition" (Frost & Massagli, 2008, p. 1). PatientsLikeMe is similar to OSGs in that they have a forum capability available for their registered users, with the exception that even though the site covers multiple conditions, the number of them is more limited. On one hand, results from Wicks et al.'s (2010) study show that respondents agreed that the PatientsLikeMe site helped them to understand their prognosis, to improve their ability to cope with their problems and made them feel more in control of their condition. On the other hand, one of the issues with sites such as PatientsLikeMe is that, as reported by Munson et al. ’s (2013) study, it not only aggregates but also *sells* de-identified data to its business partners; this might make people sensitive to privacy concerns refrain from registering and participating.

Despite the fact that social networking sites’ popularity continues to increase for all sorts of topics, (Kitzmann et al., 2011), and that, as reported by Moorhead et al.’s (2013) study, “Social media is changing the nature and speed of health care interaction between individuals and health organizations” (p. 4), and there is still limited evidence of how effective using peer-to-peer information and support provided through these applications can be in making a positive impact on people’s health. More research is also needed to establish whether social media improves health communication practices in the short and long terms (Colineau & Paris, 2010; Moorhead et al., 2013).

2.5.5. COMPARISON WITH FACE-TO-FACE GROUPS

Since there are no known research studies regarding health consumers’ information use behaviors in online support groups, it was important for the researcher to review work on equivalent face-to-face environments where participants' information exchanges can also affect their information use behaviors.

Previous research, such as that of Salem, Bogar and Reid's (1997), had described mutual help groups as “groups consisting of individuals facing similar life difficulties who come together to help themselves and others” (p. 190). They also described these groups as a source of ongoing peer-based social support, as well as a source for a psychological sense of community that may lead to a decrease in feelings of stigma and social isolation. All these behaviors described in previous research are not too much different from what is expected from online support groups today.

In terms of the ratio of gender participation, research results seem inconsistent. Some research on traditional face-to-face support groups have indicated that female participation is greater than men's (Galdas, Cheater, & Marshall, 2005; Lane & Addis, 2005; Mackenzie, Gekoski, & Knox, 2006); In contrast, other researchers have found online support groups reporting more equal participation rates between males and females (Fernsler & Manchester, 1997; Klemm et al., 1999; Mo et al., 2009).

Other empirical studies (Ogan, 1993; Hert, 1997; Winzelberg, 1997) indicate that the majority of messages posted to the online groups are produced by a small number of participants; whereas in face-to-face groups, participants engage in turn-taking, and there is a moderator who keeps the flow and encourages even participation. Face-to-face support groups are also likely to have introverted or shy participants who refrain from commenting.

There are a couple of characteristics unique to the online support groups which are not possible in face-to-face groups. These features include: participation can be passive or invisible as in the case of lurkers[15] (Burnett, 2000; Savolainen, 2001); early discussions can be retrieved from archives and used as evidence (Savolainen, 2001); visual distractions such as facial and body expressions, gender, appearance, and social status are eliminated (Han & Belcher, 2001; Martin & Youngren, 2002); and participants can achieve greater anonymity and privacy (Klemm et al., 1999; Han & Belcher, 2001; Weisgerber, 2004), among others. Other more negative characteristics that are unique to the online groups include the inability to share nonverbal communication signals; time lag between a participant request for information or support and the time a response is posted; the longer time needed to develop trust in other members (Martin & Youngren, 2002).

It is important to note that in all online support groups there are some other people “listening” to the discussions who are not actively participating.

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[15] Lurkers are described as people who take a passive participation role (only reading messages) within online communities.

These people are commonly called lurkers, silent, or non-active participants. According to Sun, Rau and Ma's (2014), the size, topic, and culture of an online community may influence lurking behaviors. Their research describes some examples where small communities can have fewer members but higher participation rates than larger online communities which can cover various topics because lurkers may be considered posters. But, even though lurkers' behavior may be used as a metric for online influence (Edelmann, 2013), this investigation focused only on actively engaged participants since the research's central point is to look into online health information use through interactive communications, and there is no interaction with silent participants.

Factors boosting the popularity of online support groups over their traditional face-to-face counterpart have been described by several researchers (Klemm et al., 1999; Savolainen, 2001; White & Dorman, 2001). These factors include: the increased availability of Internet communication technologies; better capacity to provide information and support without the inconvenience of meeting times and far away locations; an increased sense of anonymity; contact with others anywhere in the world going through the same or similar experiences, especially in cases of rare diseases where no other form of support exists; and no restriction on the number of participants the online group can have.

Understanding why health consumers go to online support groups, what the current research online support groups is, and how they compare with other social media technologies as well as with traditional face-to-face groups is important because it provides a perspective not only on how participation in this groups helps health consumers with their unmet health information needs but also on how this trend is likely to continue with people's increasing involvement with social media even for health related issues.

2.6. INFORMATION USE BEHAVIOR DOMAINS IN THE LITERATURE

This section will focus on describing the information use behavior domains (cognitive, affective, and behavioral actions), how are they defined and used by previous research, and how they will be interpreted in this research.

The notions of cognitive, affective, and behavioral domains are inconsistently defined in the literature and not all researchers consider the three of them in their perspectives. Over the years, several researchers have talked about the need for models about the information-seeking process to include characterization of both internal (unobservable) and external (observable) behaviors (Wilson, 1981; Krikelas, 1983; Brown, 1991), but most of them have focused on the observables, which as Savolainen's (2007) points out, "When looking at information behavior as a whole, it is not easy to specify how unobservable cognitive behaviors affect and orient observable information behaviors and vice versa” (p. 117). This study agrees with the notion mentioned above that information-seeking and use research should include both internal and external behavior perspectives and look into the cognitive, affective, and behavioral health information use behaviors disclosed by participants to other peers in the online support groups selected for the study.

For example, Brookes's (1975) highlights the importance of understanding the interactions of people and information through the study of “cognitive interactions” only. Some other researchers’ (Pelz, 1978; Beyer & Trice, 1982) talk in terms of conceptual, instrumental, and symbolic utilization, but this classification is mostly used in research in the organizational knowledge utilization area. Similarly, Dervin and Nilan's (1986) indicated that a problem of the system-centered approach was being limited to the external behaviors and suggested that, in contrast, one of the features of their user-centered approach was that it took into account both issues, the internal (cognitive) as well as the external (procedural).

Researchers Dervin, Harlock, Atwood and Garzona's (1980); Dervin and Nilan's (1986) work talk in terms of “utilities and help categories” constructed reflecting cognitive and affective dimensions. Since then, others, including (Nahl & Tenopir, 1996; Wilson, 1997a; Pettigrew et al.,

2001) have also incorporated aspects of internal behaviors (such as cognitive and affective behaviors) in their models; these are major points in this research as we try to understand how information is used within online peer support groups.

In her research, Kuhlthau's (1991) speaks in terms of physical, cognitive, and affective domains of activity that allow a person to move from the initial states of information seeking to the goal state of resolution. Likewise, Nahl's (1997, 2001) defines the behavioral domains as affective (A), cognitive (C), and sensorimotor (S) behaviors. In Nahl's (1997) view, these domains occur as in a sequence:

> There are intentions or information needs (A), which lead one to thoughts about solutions (C), which resolve in some related action (S). In this approach, everything that a searcher can feel or choose (A), think or infer (C), or overtly see or do (S) is considered an information behavior. (p. 13)

Other researchers, such as Pettigrew et al. (2001) state that “the cognitive viewpoint provides an important perspective since it’s interested in studying how an individual applies its model of the world to the process of needing, seeking , giving, and using information” (p. 47), or in other words it focuses on how each person thinks or behaves in response to information needs.

Similarly, Spink and Cole's (2006) talk in terms of individuals engaged in sense-making, by building a bridge over a gap, where part of “the bridge is about how the information will be used and another part about the situation of the user” (p. 27), which may include cognitive, affective, or behavioral aspect of uses.

Overall, understanding and differentiating each of these cognitive, affective, and behavioral elements is important because they can affect how we relate to information. For this research, we would refer to these domains as cognitive behavior, affective behavior, and behavioral actions describing the different ways health consumers make use of information.

2.7. FRAMEWORK FOR THE STUDY

This section describes the framework used to guide the data collection and analysis for the research questions.

Since information use studies are generally referenced as part of the information search process, then Kuhlthau's (1991) suggestion that “a model representing the user’s Sense-Making process of information seeking ought to incorporate three realms of activity: physical, actual actions taken; affective, feelings experienced; and cognitive, thoughts concerning both process and content” (p. 170) is a good and appropriate consideration for this study.

A framework for what seems to incorporate these three realms is the model of ecological constructionism. This model, as described by Nahl's (2007b) study, assumed that “important identifiable elements of information behavior in context may be classified into three biological channels of activity,” (p. 324) which she describes as affective, cognitive, and sensorimotor. This assumption “is made possible because people spontaneously use the three domains in describing their own information behaviors” (p. 324).

The model of Ecological constructionism was chosen as a good fit for the study because it, as described by Nahl's (2007a), “may serve as a common focus for disparate efforts in investigating information behaviors and information use in social technological context” (p. 2023), more specifically because it considers the threefold mental biological components (cognitive, affective and sensorimotor) of what people do when interacting with information technology to search for information. The framework also considers that “all users belong to a social group or community in which where there are shared practices for interpersonal communication, information exchange, and the management of technological devices” (Nahl, 2007a, p. 2024) which is exactly the environment of the online support groups this study is based on.

Nahl's (2007a) formal definition of the model states: “Information behavior is directed by social communication, operates through individual biological procedures, and interacts with technological information devices” (p. 2023). The model has three steps which are described by Nahl's (2007b) as follows: (1) the ‘satisficing phase’ that includes noticing, appraising, and evaluating the information, (2) the ‘optimizing phase’ which include the affective, cognitive, and sensorimotor behaviors and (3) the ‘affordances phase’ which include the satisficing and optimizing affordances.

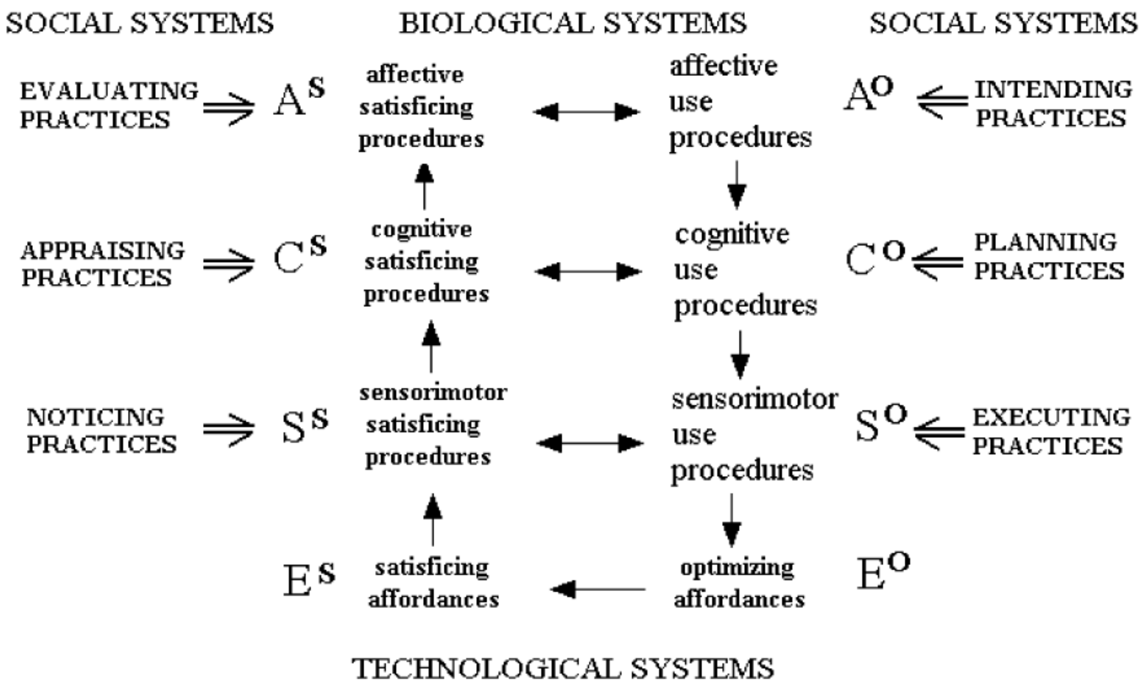

Figure 2.2 Technological systems in the Ecological model of constructionism (Nahl, 2007a)

The ecological model starts with the satisficing phase that includes noticing, appraising, and evaluating. This phase goes from the moment when an information gap occurs up until the satisficing moment when the individual stops looking for information. The second part of the model, the optimizing phase, is what this research will use the model for. It starts with the intention to use information, followed by planning a course, and ends with performing motor actions. As explained by (Nahl, 2007b), testing of the model requires analyzing discourse that is elicited from users while performing tasks. In this research, the threads of conversations contain the moment when each participant was sharing information or disclosing its use to others within the online support groups of the study.

In the ecological model, these domains follow a continuous progression, starting with evaluations of intentions (affective channel), of thoughts (cognitive channel), and of doing something (sensorimotor channel). In this research, because it is possible and likely that people do not disclose everything to other in the OSGs, then the type of information uses that do get disclosed could be any one in the progression that they chose to present to others. Thus, for example when a participant receives some answers to a question, according to the model that should initiate an affective use procedure then a cognitive use procedure and last a sensorimotor procedure but in reality, the participant might be interrupted and not go through all the steps, or even if he does all the steps, he still might only disclose part of the uses or none at all.

Thus, when we look at this research through Nahl's (2007a) model, we can see that when some chronically ill people with different kinds of information needs go to an OSGs to ask/post a question, then the moment in which they notice a response would be initiating the “noticing something” stage (step 1). When the participant starts evaluating the reply information, in order to understand it, we would be in the “appraising practices” stage (or step 2). Then when the cognitive appraisal is completed meaning is assigned to the information (Nahl, 2007a). Then the third step consists of the affective evaluation of the information “evaluating practices” or where feelings are attached to the information (step 3). At this step, the participant is deciding how he feels about the information (good to what is needed for or need more).

If the information is positively evaluated by the participant, meaning he shows intent to use it, then the information use steps start, first of which is called “intending practices” (or step 4). If for some reason the participant is interrupted here this intending practices will represent an Affective information use in this research. If the process is not stopped then in the next step, the participant will state “planning practices” or cognitive thinking, problem solving thoughts as a resulting from the information received (step 5). The process can again be stopped here for any reason that would represent participant Cognitive IUs. If the process continues then the next step includes performing sensorimotor actions “performing practices” (or step 6) which in this research refers to the behavioral IUs. This research focuses on (Nahl, 2007a) steps 4 to 6 about information use (right side of the model).

By looking at health support groups, the researcher expects to find that because people with different health conditions are expected to have different information needs then it is also expected there will display different cognitive, affective and behavioral information uses.

The importance of this research to understand the impact of consumer’s health information use in OSGs is supported in the literature, especially by Sundar et al.’s (2011) proposition that “as the influence of online health information continues to rise, health communicators and medical practitioners alike are asking questions that require greater scientific understanding of the nature, uses, and effects of online health” (p. 192).

2.8. SPECIFIC RESEARCH QUESTIONS

In order to answer the general bigger picture questions stated in chapter one, the following more detailed research questions were established:

RQ1: What types of information use behaviors are disclosed in online health support groups according to participants' characteristics?

1a: What specific cognitive information use behaviors were disclosed?
1b: What specific affective information use behaviors were disclosed?
1c: What specific behavioral information use actions were disclosed?

RQ2: How do message characteristics relate to the information use behaviors disclosed by participants?

2a: In terms of the health-related message content (CT)?
2b: In terms of the types of questions asked (QT)?
2c: In terms of the functions of the reply messages (FM)?

The first question intended to find the specific information use behaviors reported by the OSG participants based on their gender and condition (life-threatening vs. non–life-threatening chronic condition). The second research question tested whether those information behaviors disclosed in RQ1 showed any association with the message characteristics of content, question type, or the function of the reply messages.

These research questions can be justified by results from Ankem's (2007) who stated that "participants diagnosed with non–life-threatening, symptomatic uterine fibroids—had a great need for almost all types of information" (p. 170). This concurs with Murray, Burns, See and Nazareth's (2006) statement that "people with chronic disease wanted more, and better information about their health problems and the various treatment options available” (p. 4). In contrast, not all patients with cancer, a life-threatening chronic illness, wanted further information at all stages of their illness (Leydon, Boulton, Moynihan, Jones, & Mossman, 2000).

CHAPTER SUMMARY

This chapter has outlined the major areas of literature that were relevant to the understanding of how information use is currently perceived and what approaches, if any, were used to measure information use. The lack of research showing how information from OSGs is used is partly due to the fact that there is still ambiguity regarding what information use means, evidenced by the fact that the term is still inconsistently defined.

Overall, the studies reviewed here related to online health information, online support groups, and information utilization or lack of it allowed us to get a better grasp of the need for research that combines all of them into what this research proposed which was: first, to gain understanding of what actions, thinking, and feelings occur after the information is used by the health consumers, and second, how those actions, thinking, and feelings vary, if at all, across the different chronic conditions according to the types of message content, questions asked, and the function of the reply messages.

CHAPTER 3: METHODOLOGY

3.1. INTRODUCTION

Information behavior research is an area that includes at least three other subareas, including information-seeking behavior, information-searching behavior, and information use behavior (Dervin & Nilan, 1986). Of these subareas, this research is concerned with the information use aspect (or alternative paradigm[16]) since according to Raya's (2012), it is still one of the least explored areas, especially for population groups such as lay people. With this in mind, the goal of this study was to gain understanding of what it means that health consumers use information from OSGs. More specifically, the research questions guiding this investigation are:

RQ1: What types of information use behaviors are disclosed in online health support groups according to participants' characteristics?

1a: What specific cognitive information use behaviors were disclosed?
1b: What specific affective information use behaviors were disclosed?
1c: What specific behavioral information use actions were disclosed?

RQ2: How do message characteristics relate to the information use behaviors disclosed by participants?

2a: In terms of the health-related message content (CT)?
2b: In terms of the types of questions asked (QT)?
2c: In terms of the functions of the reply messages (FM)?

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[16] The alternative paradigm posits information as something constructed by human beings—"its focus on how people construct sense and on understanding information use in particular situations. It asks many how questions, e.g. how do they make use of …" (Kaye & Johnson, 1999)

This chapter explored the research design and the methodology employed in this study using a naturalistic, qualitative-quantitative combined approach within a posteriori time-space frame which measures behaviors across participants of multiple gender-based conditions that occurred after the communication event (e.g., information was gained, attitudes changed, etc) (Dervin et al., 1982b).

The rationale behind this type of approach was that, since people with different types of conditions have different symptoms, treatments, life expectancy, and so on, the information needs for each condition would likely be different. This expectation is shared by other researchers as well (Maddock, Lewis, Ahmad, & Sullivan, 2017). Ankem's (2006) research points out that different factors such as demographics, psychological states, feelings, etc can alter the need for different types of information but also that research covering this area is limited. Also, since men and women seem to have different preferences for the types of information they seek online, then we speculated that they were likely to use information differently as well. Thus, a way to combine these elements was to choose conditions specific to different genders and one control condition that would affect both genders.

The key methodological elements considered here included: assumptions underlying the research design, conceptual design, phases of the research design, data collection, data analysis, methodological challenges (including description of biases and quality issues), methodological limitations, and data analysis.

3.2. ASSUMPTIONS UNDERLYING THE RESEARCH DESIGN

This study uses the situationality assumption which states:

> "Predicting and understanding how people use information and cope with events must be based on their perceptions of how they see the situation they are in" (Dervin et al., 1980, p. 592).

The point Dervin's (1992) research makes with this assumption is that to understand information use, the focus needs to be on the actor or, in this case, the participant asking the question and not on the observers. Thus, choosing to use archived data from online discussion board conversations was a way to capture, in a nonintrusive and naturalistic way, not only how participants would describe using the information exchanged, but also their accounts of their situation.

Another assumption underlying this study refers to the uses assumption which states:

> “No matter what the intent of the source, receivers will make use of messages in terms of the helps they are seeking for the situations they are in” (Dervin et al., 1980, p. 592).

This is why the researcher considered that it was necessary to make sure that the sample of threads retrieved from the archives would include only those where the thread initiator[17] had posted at least one reply back to those who answered his/her information inquiry, because in that reply is where the thread initiator could have potentially indicated how he or she used the messages regardless of what was suggested by other participants. This condition would make it more likely to capture threads where information uses from the receiver were present.

Both of these “alternative assumptions,” as Dervin and Nilan's (1986) study called them, focus on the user’s perspective and how they construct sense and make use of information for their situations, which is exactly the focus of this study: the understanding of information use of peer-to-peer information exchanges within an increasingly popular source such as online health discussion boards.

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[17] Thread initiator refers to the participant that starts a new thread of conversation in an online forum or bulletin board.

3.3. RESEARCH METHOD

The goal of the study was to gain better understanding of how consumer health information shared within online support groups is used by participants. More specifically, this research looked into what cognitive, affective, and behavioral actions were disclosed, as well as how and whether those information behaviors conformed to any pattern of use with respect to the message content, the types of questions asked, and the function of the messages. In order to carry out this goal, the computer-mediated discourse analysis (CMDA)[18] approach was chosen. As described by Herring's (2004), this approach "provides a set of tools and a set of theoretical lenses to make observations and interpret results of empirical analysis" (p. 4). It focuses on analyzing logs of verbal interactions, which in this research refers to the interactive exchange of messages (threads of conversations), by using a content analysis technique.

In this research, since we used secondary data, participants were not available to answer the researcher's questions. Thus, the participants' information needs, that could later conduce to reports of information use

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[18] CMDA "refers to any analysis of online behavior that is grounded in empirical, textual observations is computer-mediated discourse analysis." <PLEASE check quote—in? computer-mediated…?> (Herring, 2004)

instances[19], were captured from the questions they asked within the selected OSGs. Then the researcher looked into complete threads of conversations to find if the question asker indicated how the information was used. The added advantage of this research using secondary data was that the data itself is a posteriori time-space where the measure of behaviors occurred after the communication event meaning that there would be higher likelihood of uses being reported, which Dervin et al. (1982b) indicated their research did not include.

3.3.1. CONTENT ANALYSIS METHODOLOGY

This method is defined by (Neuendorf, 2016) as the systematic, objective, quantitative analysis of message characteristics. She also points outs that:

> Even though the first steps of the process include a qualitative review of the message pool and development of an emerging coding schema based on what's represented in the pool, the true content analysis portion is the subsequent careful application of the a priori coding schema to the message pool (p. 18).

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[19] Information use instance refers to any posted message describing one or more occurrences of specific uses of a piece of information received through the Online Support Group.

Hsieh and Shannon's (2005) study adds that current applications suggest content analysis has the capability of “showing three distinct approaches: conventional, directed, or summative” (p. 1277). They describe the conventional approach as coding categories derived directly from the text data; the directed approach as analysis that starts with a theory or relevant research findings (a priori categories); and the summative approach as involving counting and comparisons followed by the interpretation of underlying context. For this research, a directed content analysis was chosen as the methodology for analysis, not only because the coding categories were selected a priori but also because, as a general text analysis technique, it is one of the most frequently and widely used by researchers with similar online research studies. This method is also a good fit for the study because it can facilitate the analysis of written discourse for archived threads of online conversations (or “trace data”[20]).

As suggested by Lee and Peterson's (1997) and Herring's (2004) studies, CMDA content analysis is not different in principle from other research

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[20] Trace data is defined as records of activities undertaken through an online information system (thus digital), which contain evidence that something has occurred in the past ((Howison, Crowston, & A., 2011)

Trace data is unique, unobtrusive, and nonreactive data. It can make for a very valuable research course of action. The collection of the data does not interfere with the natural flow of behavior and events in the given context. (Jansen, Taksa, & Spink, 2009) methods because it requires that the researcher gather suitable material, develop a coding protocol, and ascertain the reliability and validity of the actual coding by getting multiple coders to agree how the coding should be applied to the sample data, and includes direct quotations from data in reporting the findings (Johnson, 1997).

3.4. ANALYTICAL APPROACH

In order to study the data, this research followed steps similar to those used in discourse analysis for charting the flow of micro-information behavior in context. This technique, as described by Nahl's (2007b),was drawn from the model of ecological constructionism and is used to analyze text produced by people when discussing their self-described information practices. The method consists of coding the text into the three domains of behavior, that is, the affective, cognitive, and behavioral domains, which previous researchers such as Nahl's (2001) have argued are significant components of information-seeking behavior.

It should be noted that the terms *cognitive*, *affective*, and *behavioral information uses* have not been used consistently throughout the literature. Some researchers, such as Dervin and Nilan (1986), do not separate cognitive and affective behavior conceptually since they consider both to be interpretative responses, but they do separate them descriptively. Other authors, such as Nahl's (2001), talk about these terms as “an ordered sequence (affective-cognitive-sensorimotor) where affective behaviors must meet their appropriate cognitive mates to produce the effective sensorimotor outcomes" (p. 3).

In this research, these terms will be considered as described here:

> *Cognitive behavior* refers to any direct reference to changes in a person's thoughts or way of thinking as a direct result of applying information received from online support groups (Todd, 1999b; Nahl, 2001).
>
> *Affective behavior* refers to any direct reference to expressing feelings experienced as a direct result of applying information received from online support groups (Dervin, 1992; Nahl, 2001).
>
> *Behavioral actions* refers to any direct reference to specific actions, physical changes in end-states, impacts, practices, and procedures as a direct result of applying information received from online support groups (Todd, 1999b; Nahl, 2001).

In her research, Nahl's (2006) explains that "by charting the flow of people's micro-information behaviors in context, what it is obtained is an empirical representation of many details of how people actually process information and how they make use of that information" (p. 324). Hence, for this research, the coded text corresponded to the phrases, sentences, or paragraphs that described features in the three domains:

- The Function of Reply Messages variable looked into classifying the intended purpose or purposes (there can be multiple functions) of each reply message within each thread using the respective coding schema.

- The Information Use variable looked into finding information use instances within each posted message (there can be multiple information use instances within each post.) An information use instance refers to any sentence or paragraph describing a specific cognitive, affective, or behavioral use given to a piece of information received through interactions within the online support group. For example, the following extract from a post shows an information use instance.

  > I've known I've had [XXX] for about [XX] years but I didn't really know much about it until I finally decided to look information up on the Internet. Since I have been reading everyone's posts I've realized I don't know much about my own condition so I am going to be asking for a copy of my chart from my doctor to read about it.

- The Content Type variable looked into classifying each complete message according to the kind of medical content that is associated with any disease or health condition using the respective coding schema (there can be multiple content types).

- The Question Type variable looked into coding each sentence containing a question expressing the information need of the participant using the respective question type schema (there can be multiple questions within each post).

3.5. RESEARCH DESIGN OVERVIEW

The study was conducted in three phases, described in the table below:

Table 3.1 Phases of the Research Design

Phase	Activity
Phase 1	✚ Selection and development of coding schemas. ✚ Selection of sites ✚ Selection of health conditions.
Phase 2	✚ Data collection using conditional systematic sampling. ✚ Coding of the selected sample using the chosen schemas. ✚ Intercoder reliability tests of coded data, one or more times as needed to reach acceptable coder agreement scores.
Phase 3	✚ Data Analysis using content analysis. ✚ Computation of some basic statistical measures. ✚ Interpretation of data and reporting of findings.

3.5.1. RESEARCH DESIGN OVERVIEW: PHASE 1

Phase one of this study consisted of: selection and development of coding schemas, selection of the data sites, and selection of health conditions for data collection, all of which had some challenges to overcome.

Some of the challenges related to creating the coding schemas occurred because there were few appropriate schemas to measure information use in general or to measure information use from sources such as online support groups. Thus, for this study, the researcher used modified a priori coding schemas based on indications by researchers, such as (Henri, 1992) and (Miles & Huberman, 1994), that analysis that uses categories established a priori enables to concentrate on more specific aspects of computer mediated communication . Following this approach, some of the schemas chosen for the study were used exactly as they were published, and others were adapted to achieve the study's goal. The adapted schemas were revised and modified as necessary, based on the pilot data analysis (for complete details on the process see Section 3.6).

3.5.1.1. SELECTION OF THE POPULATION

To search for the appropriate online discussion boards, the researcher consulted and used major online search directories, engines, and portals (such as Yahoo, Google, AltaVista, ivillage, WebMd) listing disease-specific electronic bulletin boards, as well as major governmental and nonprofit organizations' portals that are related to the specific conditions of the study (prostate and ovarian cancer, and infertility) and either clicked on a link to get access to the different boards or typed in a search for discussion boards; finally choosing the ones related to the three specific chronic conditions being studied.

The selection of the online discussion boards' population was based on a preliminary screening of groups with an active but not overwhelming daily posting traffic, groups having a relatively large number of participants and which have existed for at least a couple of years (to ensure they are stable), groups which permitted the use of their data for research purposes (determined based on their privacy statements or terms of use, if they said anything at all), and groups for which messages had some level of threading.

3.5.1.2. SELECTION OF THE SITES

There was some difficulty with the selection of the sites for data collection, due to the fact that not every health portal related to the conditions chosen for the study has a discussion board. Among several of the sites that did have a board, not all of them were active enough—the site needed to have lots of members, with at least 50 messages posted within the last 30 days of data collection to be worth selecting a sample from it. (These numbers are based on suggestions from other researches into what the minimum participation within an active board should be.) (Silence, 2013).

Those boards that are very active and well known restrict their access for research purposes and require a membership or password for access. The researcher selected three to four sites among the ones that did not have any of the previously mentioned limitations for each of the conditions being studied.

Among the online support groups selected for this study are the two in the American Cancer Society Cancer Support Network (ACS, 2017a) one for prostate and one for ovarian cancer. Both of these support groups allow survivors as well as caregivers to satisfy not only their need to talk about their experiences with cancer, but also to discuss various aspects of their cancer experience, such as diagnosis, treatment, relationships, coping, overcoming any feelings of isolation, and just daily living with cancer.

Another of the specific discussion sites selected was Fertile Thoughts.com at (FertileThoughts, 2017). In this forum, several different aspects of the infertility problem are kept in separate discussions. The researcher selected a sample, including several of the more frequently discussed aspects, based on their volume of postings. In all cases the support groups allowed participants to discuss issues about their diagnosis, treatment, the effect on relationships, coping, and alternative resources that could help them deal with their infertility concerns. For a complete list of selected online boards for each of the conditions and their respective URLs, see Appendix B.

3.5.1.3. SELECTION OF HEALTH CONDITIONS

There are hundreds of health conditions, any one of which could be a good candidate for this study, but not many of them have as much coverage or as lengthy a coverage period in different media as cancer and infertility do. Also, as indicated by Davison et al.'s (2000) study, cancer patients exhibit the highest overall tendency to seek and offer support, so they become, for practical reasons, a more convenient group to sample, since their messages have a higher likelihood of containing information use instances. It would certainly be interesting and more representative to study several different conditions, but since that is not feasible in terms of time, it was decided that three medical conditions would be enough for this study.

Cancer is one of the leading causes of death in the United States, as reported by statistics from government agencies (CDC—Centers for Disease Control, NCHS—National Center for Health Statistics) and other organizations (American Cancer Society, National Cancer Institute). Another criterion for the selection of cancer is that several cancers are gender-based conditions, so the researcher could observe if the information needs and information use behaviors of the health consumers would vary by gender. A sort of "control condition," a condition that can affect both genders, that is, infertility, was also selected, to allow comparison of its related information use behaviors with the two previously selected gender-based conditions. Infertility is seen as “one of the most common chronic health disorders in young adults. In the United States, the prevalence of infertility has been estimated to be 15 to 20%, affecting more than 6 million couples” (Jacob, 2012, p. 19). Also, previous research about infertility (Malik & Coulson, 2008b) underscored the need for better understanding of how infertile couples use online infertility support groups.

Another dimension for the selection of the conditions was whether they were life-threatening vs. non–life-threatening chronic conditions. The importance of this dimension was based on the fact that chronic but nonfatal conditions (such as infertility) are very different from those chronic and potentially fatal conditions (such as cancers) where people can feel stigmatized or debilitated and as a consequence become less willing to participate in forms of support that could be helpful to them. Based on these dimensions, the conditions selected included: ovarian and prostate cancer, and infertility, each of which is described below. Another relevant reason for studying information use on populations with chronic conditions is the fact that nearly half (45%) of adults in the United States are living with at least one chronic condition (Fox; & Purcell, 2010).

Ovarian Cancer (OC) “Ovarian cancer is a disease in which, depending on the type and stage of the disease, malignant (cancerous) cells are found inside, near, or on the outer layer of the ovaries. An ovary is one of two small, almond-shaped organs located on each side of the uterus that store eggs, or germ cells, and produce female hormones estrogen and progesterone” (NOCC, 2017). According to the American Cancer Society, ovarian cancer ranks fifth overall as a cause of women’s cancer deaths (ACS, 2017b).

Prostate Cancer (PC) “Prostate cancer begins when cells in the prostate gland start to grow uncontrollably. The prostate is a gland found only in males” (ACS, 2017c). The American Cancer Society indicates that “prostate cancer occurs mainly in older men. About 6 cases in 10 are diagnosed in men aged 65 or older, and it is rare before age 40. Other than skin cancer, prostate cancer is the most common cancer in American men” (ACS, 2017d).

Infertility (IN) “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” (WHO, 2017). According to the Center for Disease Control and Prevention (CDC), “about 12% of women aged 15 to 44 years in the United States have difficulty getting pregnant or carrying a pregnancy to term” (CDC, 2017). Approximately one-third of infertility is attributed to the female partner, one-third attributed to the male partner, and one-third is caused by a combination of problems in both partners or is unexplained (ASRM, 2017).

3.5.2. RESEARCH DESIGN OVERVIEW: PHASE 2

Phase 2 was composed of the following steps: data collection, data coding, and intercoder reliability testing.

Once the sites were selected in the previous phase, the data collection process was relatively straightforward. Even though the research data would come from the archives, before collecting the data, the researcher requested IRB approval from the university. The IRB granted approval as exempt research whereupon the data collection process began.

The first step in collecting the data consisted of deciding on the selection strategy, followed by going to each selected board and downloading the threads. The key issue here was the selection strategy. In order for the data to be appropriate for the research, the researcher used a conditional systematic sampling where each unit selected needed to satisfy certain conditions or rules in order to be selected (See Section 3.7.2 for explanation of rules for selection and more details on the sampling process). Fifty (50) message threads were collected for each condition for a total of 150 threads yielding 1,099 posts to be analyzed (see Section 3.7.3 for explanation why this amount was considered appropriate for this research).

When coding the data, first we looked into each thread, and for each thread, we looked into each post, then for each post, we looked into all demographic codes, all Content Type codes, all Function of Reply Messages codes, all Question Type codes, and all Information Use codes (cognitive, affective, and behavioral categories) following the coding schemas rules described in the codebook instructions (see Appendix C) and assigned the ones that were appropriate for each. Once all different variables were coded then in order to analyze the findings with respect to the presence of information use instances and the other variables then we look at the whole thread as an aggregate. For an illustration of this general process see Figure 3.1 below and for specific details about the analysis with the aggregate data see section 3.10.

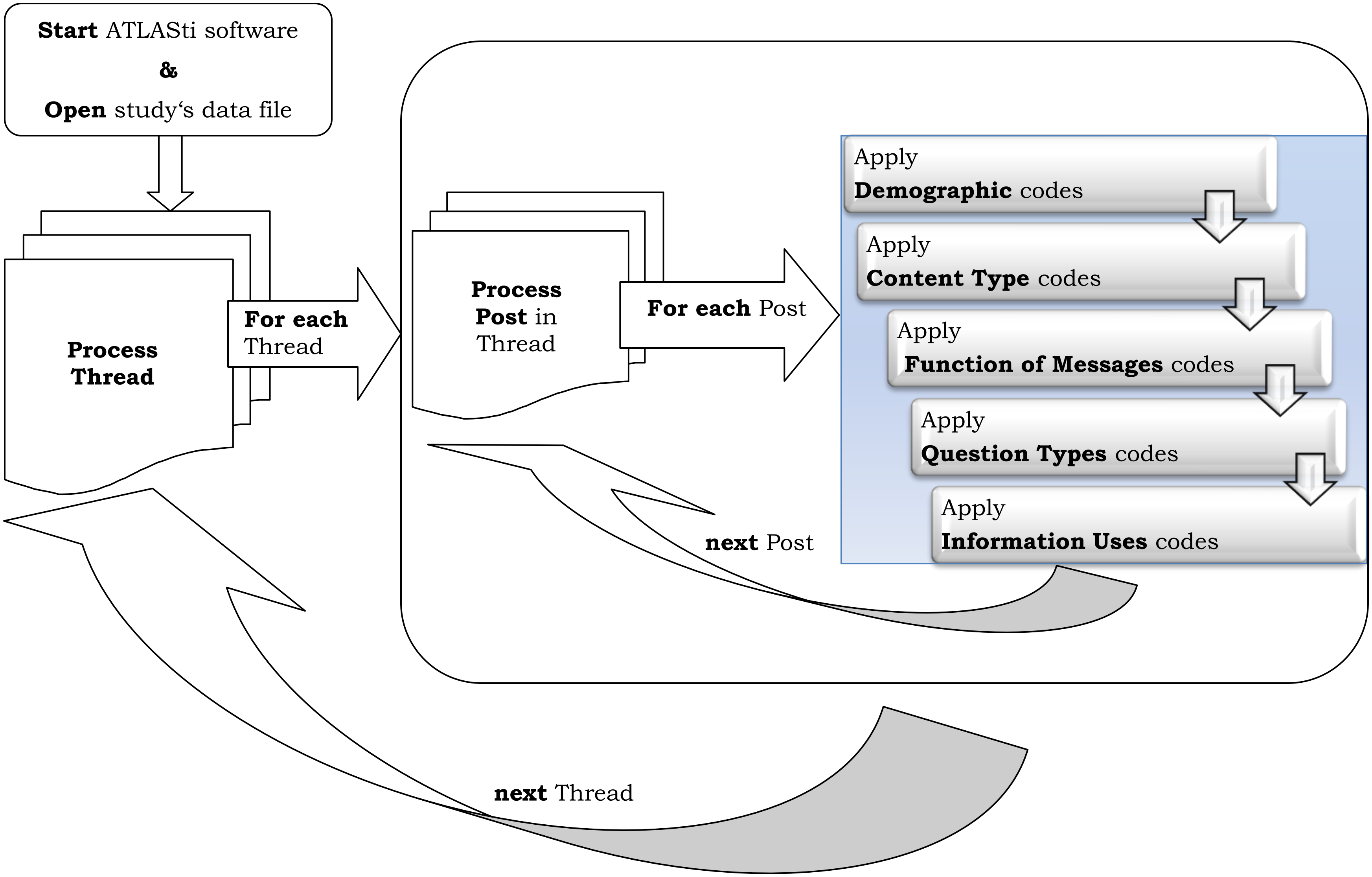

Figure 3.1 Data Coding Process

The data analysis step consisted of using the content analysis technique to analyze threads of messages from the selected health bulletin boards, computing some basic quantitative statistical measures afterward in order to give a better, although still limited, characterization of the sample. The coding variables and schemas used for the analysis are briefly described in Section 3.7 and the complete codebook appears in Appendix C.

The last step in this phase was to compute intercoder reliability scores. We computed these scores on for 12% of the data. Between 10 and 20% of the data is a frequently used guideline by researchers although, unfortunately, there is no a set standard for this number (Neuendorf, 2016). The data was compiled from each of the three conditions being studied (about 18 threads) to assess the reliability of the coding schemas and determine whether the schemas needed to be improved by collapsing or eliminating some of the categories. A decision to collapse categories occurred when the line between one or more subcategories was not as clear and decisions were difficult because they seemed to cover the same elements. A decision to eliminate a subcategory, however, was due to zero frequency of occurrence across all conditions.

The revision of the coding schemas was based on intercoder reliability tests (see Table 3.17, percentage agreement coefficients) and results from the pilot data analysis. When coding differences were found, the researcher and coder discussed the coding schema until a consensus was reached. After the needed adjustments were performed (see adjustments in Appendix E), a reevaluation of that part of the coding on the pilot data was done before coding the complete sample. Once all the coding was done using the adjusted schemas, then the data was ready to be analyzed.

3.5.3. RESEARCH DESIGN OVERVIEW: PHASE 3

The last phase of the research process consisted of two steps: first, data analysis, and second, interpretation of the data and reporting the findings.

The interpretation of the data was targeted to answer each of the research questions, looking into possible implications for future research and preparing the findings for reporting of the results.

In reporting the results, because the raw data is extensive and difficult to present, the researcher worked on ways to describe the findings simply by incorporating some typical examples from the data when possible. In this way, as pointed out by Graesser, Person and Huber's (1992), the researcher would be able to demonstrate adequate connections between the researcher's abstraction and the data.

3.6. SELECTION OF CODING SCHEMAS

In this study, the researcher applied several different coding schemas to analyze the data; some were taken exactly as they appear in the literature and others as compilations of other researchers' work. The intent of these coding schemas is to identify the cognitive, affective, and behavioral information uses reported by participants, as well as determine if the types of questions asked and the function of the messages or the medical content have any relation to the types of uses participants reported experiencing.

The coding schemas chosen and developed for the study appear to be sufficiently expressive; revealing all the important elements, because no other categories seemed to be needed after the coding was done. There were several subcategories in the different schemas with zero incidences. Of course, this is true only for the specific data of this study but may not necessarily be the case for health conditions not studied or even for analyzing information use in support groups in other areas. This means that testing the schema further would be necessary to make it more broadly applicable to analyze the cognitive, affective, and behavioral impacts of using information from online social media.

❖ Question Type Coding Schema

Understanding what kinds of questions were asked by participants in the online support groups was important because it would potentially allow the researcher to assess whether and which of those types of questions showed an association with the types of information uses disclosed by participants.

In terms of the kinds of questions asked, it is important to point out that since request for advice within OSGs is often not presented in a straightforward manner, the implication is that several indirect questions or expressions of needs can be treated as requests for advice (Morrow, 2006; Zhang & Fu, 2011; Stommel & Lamerichs, 2014).

The coding schema shown in the following table (Table 3.2) refers to Graesser, McHahen and Johnson's (1994) taxonomy of question types. This question type schema was chosen because, besides being one of the most well-known taxonomies of questions, it had been previously used by several other researchers that coded questions in discourse. It is also a very flexible typology since it contains a rather broad list of types of questions that allow capturing complex insights into the information needs of participants in a wide variety of settings for many purposes (White, 1998a). Graesser et al.’s (1994) categories were used in this research to classify the different types of questions asked in the board conversations, especially those stated by the thread initiators. All the categories are those from Grasser et al. (1994), with no changes other than adding examples related to health information.

Table 3.2 Subcategories of Question Type: Graesser et al.'s (1994) Taxonomy

Question Type: Definitions & Examples	
Assertion	The poster makes a statement indicating that he lacks knowledge or does not understand the information. *Ex. I don't understand what the results mean*
CausalAntec	The poster wants to know what prior state or event causally led to some particular event. *Ex. What did the doctor do to prevent patient getting worse*?
CausalConse	The poster wants to know what the effects of an event or state are. *Ex. What are the effects of taking this drug*?
Comparison	The poster wants to know how is X similar to (or different from) Y. *Ex. How is chemo similar to radiation*?
ConceptCompletion	The poster wants answers to Who/What/Where/ When questions about states, events, or actions. *Ex. What kind of testing do they do to determine if you have the condition*?
Definition	The poster wants to know: what does X mean? *Ex. What does Endo mean?*
Directive	When a poster wants other participants to perform an action and it is presented more forcefully than a request. *Ex. Call me when the results are ready.*
Disjunctive	When the poster wants to know which one of two or more alternatives is true. *Ex. Is the therapy effective for male infertility or for female infertility*?
Enablement	When the poster wants to know what object/states resources/abilities allow agents to perform actions? *Ex. What kind of feedback will help you make a decision*?
Example	When the poster requests an example. *Ex. Could you give me an example of how that treatment worked for you*?
Expectational	When the poster wants to know why an expected event or action did not occur. *Ex. Why didn't the treatment work*?

FeatureSpec	When the poster wants to know the value of an attribute or which features (shape, form, sound & picture) are informative. *Ex. What does the X-ray show*?
GoalOrien	When the poster wants to know the reasons and motives behind an intentional action. *Ex. What will you do with the information you get*?
Instrumental	When the poster wants to know what instrument allows an agent to accomplish a goal. *Ex. What is the plan to increase my fertility and ovulation*?
Interpretation	When the poster wants to know what concepts or claims can be inferred from a static or active pattern of data. *Ex. What do these different PSA levels mean*?
Judgmental/Eval	When the poster wants the respondents to provide him with advice about what actions to take. *Ex. Would that treatment be too aggressive*?
Procedural	When the poster wants to know what plan (set of acts or process) allows an agent to accomplish a goal. *Ex.* How can I lower my PSA level?
Quantification	When the poster wants to know the magnitude (how much, how many) or frequency (how often) of an attribute. *Ex. How much time* does *embryo* implantation take*?*
Request	When the poster politely asks another participant to perform an action. *Ex. You should make an appointment*
Verification	When the poster wants an implied yes/no/maybe /who knows answer, or when questions on the surface appear disjunctive but have only one answer. *Ex. Does she have nerve pain*? *Is she in pain or not*?

❖ Function of Reply Messages coding schema

Understanding the function of the reply messages was important because every message is written with a purpose (or function) and that purpose may affect the kinds of responses given or the types of uses given to the information (similar to some coping strategies[21]). Thus, the researcher wanted to determine if the possible effect of the function type could also occur with health information shared within online support groups.

The Function of Reply Messages coding schema was put together as a modified version of Bales's (1951) Interaction Analysis Categories with Klemm et al.'s, (1998) Response Categories, identified in an Internet cancer support group. Klemm et al.'s categories, which included (Information giving/seeking, Personal Opinions, Encouragement / Support, Personal Experiences, Thanks, Humor, Prayer, and Miscellaneous) were used as the basis for the Function of Reply Messages schema because their categories were also based on work about online health support groups and because the categories seemed to cover a broad list of the types of replies found in a preliminary review of the data. Then Bales's (1951) categories were combined with Klemm et al.'s, (1998) categories, because this would allow us to define a more specific set of problem solving subcategories. A few new categories for Information Usefulness, Information Use, and Board issues were added to address concepts specific to this study that were not part of either of

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[21] Coping strategies are the behaviors, thoughts, and emotions that you use to adjust to the changes that occur in your life. UCLA Dual Diagnosis Program, 2016. https://www.semel.ucla.edu/dual-diagnosis-program/News_and_Resources/How_Do_You_Cope

their schemas. That integration resulted in the Function of Reply Message (FM) scheme shown in Table 3.3 below:

Table 3.3 Sources of Each Function of Reply Messages Subcategory

CODE SUBCATEGORY	SOURCE
FM-01_Info_Seeking (AsksOrientation, AsksOpinion, AsksSuggestion)	(Klemm et al., 1998) (Bales, 1951)
FM-02_Info_Giving (GivesOrientation, GivesOpinion, GivesSuggestion	(Klemm et al., 1998) (Bales, 1951)
FM-03_Describe_Experience	(Klemm et al., 1998)
FM-04_EncouragSupport	(Klemm et al., 1998) (Bales, 1951)
FM-05_SocEmotional_Iss	(Bales, 1951)
FM-06_Humor	(Klemm et al., 1998)
FM-07_Thanks	(Klemm et al., 1998)
FM-08_Prayer	(Klemm et al., 1998)
FM-09_Ack_InfoUsefulness	This research
FM-10_Ack_InfoUse **FM-10.01_Ack_CognitiveIU** **FM-10.02_Ack_AffectiveIU** **FM-10.03_Ack_BehavioralIU**	This research
FM-11_BoardIssues (TechBoard_Iss, AdmBoard_Iss)	This research
FM-12_Miscelaneous	This research

The following table (Table 3.4) shows examples extracted from the data for each of the FM subcategories. It’s important to mention that each message can have multiple functions, but the examples for each category here were selected from different posts.

Table 3.4 Subcategories of Function of Reply Messages

Code SubCategory	Examples
FM-01_Info_Seeking (AsksOrientation, AsksOpinion, AsksSuggestion)	Hi-it looks like nobody has written here in a month or so. I too have high prolactin (89) and have not had my period since Aug. I have an appt with an endicronologist (sp?) Thurs. Can anyway tell me what I might expect? I am desperate to start trying to conceive.
FM-02_Info_Giving (GivesOrientation, GivesOpinion, GivesSuggestion)	Everyone is different. However, I’ve done injectibles with IUI 3 times now and each time they monitored they said only follies which were 15+ would be considered mature enough to be a target egg. They do typically like to see the sizes closer together so that you have a few that will release an egg and increase your chances of getting pg. Just be careful that too many aren’t mature because of the risk of high order multiples & OHSS.
FM-03_Describe_Experience	I don’t really know the answer either, but I have high cholesterol and it never even came up in my many meetings, blood tests, etc. with my RE. I, like Hope, am trying to eat better to help lower it. My uneducated opinion is that I don’t see why you need to stop your treatments because of it. Hope that helps.

FM-04_EncouragSupport	Give yourself some more time. You will have to believe in yourself. Think about where you were pror to RP and where you are now. My PSA was 19.5 & Gleason of 4/3 and T2. All is good after 2 yrs. Even if all was not well, I would defeat it, as I have all my fellow PC survivors to support me. Keep up the faith.
FM-05_SocEmotional_Iss	I am so sorry to hear about your mom. I am a survivor of stage 3c, grade3 ovarian cancer. My sister is a survivor of 4 years. Try not to focus on the ca125 but on the fact it doesn't' sound like it has spread bad. Praise the lord for the CATscans. We will keep you both in our prayers.
FM-06_Humor	the term "ultra high PSA" is strictly my own way of describing an unusually high PSA. Like many of us who play around the internet, I am a health/ medical info junkie which sometimes creates a lot of confusion due to the flood of info, some good and some bad. Actually, urology is not my strong point, although in a few months, I think I will be able to perform roadside brain surgery (heh, heh).
FM-07_Thanks	Thank you so much to both of u for the support I really appreciate it. I'm sorry IN-Thread05_P03 your right i meant ET not implantation. My brain is totally scrambled these days. I have told my gp and i go back to the clinic soon for more follow ups. But seriously thanks I need all the support I can get right now.

FM-08_Prayer	You aren't alone in thinking it is a screwy confusing schedule. But I am praying that you get to see the heartbeat! And it is truly exciting......it looks like little flitters. Take a deep breath and you will be fine! Good luck sweetie!
FM-09_Ack_InfoUsefulness	Thanks OC-Thread… I looked at it. It was interesting.. Thanks for your help.
FM-10_Ack_InfoUse	**FM-11.01_Ack_CognitiveIU** Thanks for the review on the Cunningham Clamp. I have heard about them, but didn't know how effective they were. It seems to be working great for you. I might try one myself if my incontinence doesn't improve soon. Take care**.** **FM-1.02_Ack_AffectiveIU** My PSA is <0.1 My Dr didn't explain it to me like you did but your explanation is really encouraging. **FM-11.03_Ack_BehavioralIU** thanks for the info will have to check it out! I know anything that we can take to help our healthy cells to thrive is always good…Continued good luck on your cancer journey…
FM-11_Board_Issues (TechBoard_Iss, AdmBoard_Iss)	Received your email and questions- tried to respond but had difficulty with page and lost your separate email inquiry. Please resend me email so I can respond privately to your questions.
FM-12_Miscellaneous	Looks like it's just a coincidence then, since others, not just in the CSN groups are getting the same spam. I've heard the same thing about deleting without opening, but still they come!

❖ Information Use Coding Schemas

The Information Use (IU) coding schemas used in this research emerged as an integration of the work of several researchers. Its purpose was to categorize the thoughts, feelings, and actions that health consumers reported taking based on the information they received in health OSGs they participated in and classified under the cognitive, affective and behavioral categories of information behaviors.

More specifically, the IU categories were defined based on Nahl's (2001) taxonomy of information behaviors as well as Pritchard's (1974) and Sweetland's (2000) work, in which they were concerned with the effect or perception of the impact of information on patients and users of health information services, in terms of knowledge understanding, emotions, and behaviors in health environments.

Kuhlthau's (1991, 1993) research focused on the search process from the user's perspective, where, she defines, “a model representing the user's Sense-Making process ought to incorporate: physical, actual actions taken; affective, feeling experienced; and cognitive, thoughts concerning process and content” (p. 362). In addition, her researchon the principle of uncertainty for information seeking were used for defining what the major IU categories in this research are about.

The work of Dervin et al. (1980) on the nature of utility regarding patients' questions to their doctors—did they help or did they not help—was used not only to provide several of the subcategories in the IU coding schema but also because they highlighted the "nature of the situation as seen by the patient" (p. 594) which is also what the goal of this research is—looking into participants' own reported uses of the information they received.

Also, Nahl's (2001) work on a conceptual framework for explaining information behavior, and Kuhlthau's (1993) psychodynamic approach to information behavior provided several of the cognitive, affective, and behavioral subcategories used in this research. Similarly, the work of Dean's (1986) and Shuval, Javetz and Shye's (1989) on lay persons' self-care and illness coping strategies and their reported physicians' perceptions of the effects of independence and initiatives used by lay persons to cope with their illness inspired some of the behavioral subcategories.

The following three tables: Table 3.5, Table 3.6, and Table 3.7 show the subcategories for each schema and their sources.

Table 3.5 Sources of Cognitive Subcategories

COGNITIVE SUBCATEGORIES	**SOURCE**
IU-01.01_NewImprovedUnderstanding	(Dervin et al., 1980; Dervin et al., 1982b) (Sweetland, 2000)
IU-01.02_IdentifyingPossibilities	(Dervin et al., 1980; Dervin et al., 1982b)
IU-01.03_LearningManageStress	(Dean, 1986)
IU-01.04_LearningAvoidPitfalls	(Dervin et al., 1980; Dervin et al., 1982b)
IU-01.05_HowInfoIsInterpreted	(Nahl, 1997) (Sternberg, 2009) (Kuhlthau, 2004)
IU-01.06_GettingBetterInformed	(Sweetland, 2000)

Table 3.6 Sources of Affective Subcategories

AFFECTIVE SUBCATEGORIES	**SOURCE**
IU-02.01_StrengtheningSelf-feelings	(Dervin et al., 1982b)
IU-02.03_BetterAble2Relax	(Dervin et al., 1982b)
IU-02.04_FeelingConected2_Others	(Sweetland, 2000) (Dervin et al., 1982b)
IU-02.05_IncrDecrFeelings	(Pritchard, 1974) (Sweetland, 2000) (Kuhlthau, 1993)

Both Table 3.5 and Table 3.6 above, which contain the cognitive and affective subcategories, were based on Dervin et al.'s (1982b) work on the nature of utility categories because they were conceptualized as the ways in which people use information. The work from the other researchers listed helped in defining the meanings or content of some of the subcategories, as well as aided with the grouping of the subcategories into the cognitive, affective, and action behavior domains.

Table 3.7 Sources of Behavioral Subcategories

BEHAVIORAL IUs SUBCATEGORIES	SOURCE
IU-03.01_Requesting2ndOpinion	(Shuval et al., 1989)
IU-03.02_TakingMoreActiveRole	(Shuval et al., 1989) (Pritchard, 1974)
IU-03.03_TakingActionBasedOnSuggestion	(Sweetland, 2000)
IU-03.04_TalkingAboutCondition	(Dean, 1986; Shuval et al., 1989)
IU-03.05_ChangesInLifeStyleMade	(Dean, 1986; Sweetland, 2000)

The work of the researchers listed in Table 3.7 were used to inspire the behavioral action subcategories since they focused on individual's self-care health behaviors during illness as well as the behavioral effects of health facts on knowledge and understanding.

The following tables: Table 3.8, Table 3.9, and Table 3.10 show examples extracted from the data for each of the IU subcategories:

Table 3.8 Cognitive Subcategories: Examples from Data

COGNITIVE SUBCATEGORIES	DEFINITIONS AND EXAMPLES
NewImprovedUnderstanding	Getting a new or altered more realistic picture of himself or other's situations based on instructions, facts, or answers to the questions asked. Poster expresses being able to see the road ahead. *Ex. ..you make a good point. it's something 2 think about*
IdentifyingPossibilities	Poster indicates being able to identify possibilities. *Ex. …I hadn't thought about the "Depends Guards for Men" pads…*
LearningManageStress	Participant realizes the importance of learning how to manage his/her condition related to stress. *Ex. You're right. It drives me crazy that is so out of my control but I'm working on that and getting better…*
LearningAvoidPitfalls	Participant expresses learning to avoid pitfalls about what not to do, to prevent something bad, or prevent doing something undesirable. *Ex. …I had no idea that saliva could impair my chances of getting pregnant…*
HowInfoIsInterpreted	Participant expresses how he/she has interpreted, classified, or related the information received to existing knowledge. *Ex. …Yes I have read about the link between colon, breast and ovarian cancer and I think that is another reason I have my concerns…*
GettingBetterInformed	Participant indicates a more informed decision was made about a course of action, including doing nothing. *Ex. …I have since searched the web and am better informed about my own body…*

Table 3.9 Affective Subcategories: Examples from Data

AFFECTIVE SUBCATEGORIES	DEFINITIONS AND EXAMPLES
StrengtheningSelf-feelings	Participant expresses a resistance / avoidance attitude toward new information. *Ex. … It makes me feel better when I hear "happy endings…*
BetterAble2Relax	Participant expresses being better able to calm down and relax. *Ex. …Knowing people understand what I'm going through gives me some comfort…*
FeelingConected2_Others	Participant expresses feeling more connected to others. *Ex. …Certainly, I am apprehensive and it helps to hear from those who have gone through it…*
IncrDecrFeelings	Participant expresses that feelings of uncertainty, doubt, discouragement, anxiety, depression, shame, excitement, or satisfaction either appear, increase, decrease, or disappear. *Ex. …It makes me feel less defective…*

Table 3.10 Behavioral Subcategories: Examples from Data

COGNITIVE SUBCATEGORIES	DEFINITIONS AND EXAMPLES
Requesting2ndOpinion	Upon the information exchanged in the OSG, the participant requests a second opinion. *Ex. …I will have to get a second opinion…*
TakingMoreActiveRole	Participant expresses taking a more active role because of issues discussed on the board. *Ex. …I talked to the doctor to let him know that I need him to monitor my thyroid…*
TakingActionBasedOnSuggestion	Participant indicates he /she will take an action based on a suggestion given in the OSG. *Ex. …oh well. i followed your advice…*
TalkingAboutCondition	Participant expresses talking and discussing about his condition with others based on suggestions from the OSG. *Ex. I will definitely be talking to my RE about it*
ChangesInLifeStyleMade	Participant indicates lifestyle, dietary, or other changes were made based on information and issues discussed on the online board *Ex. …Wow, I'm so excited about all the tips here! I'm totally going to alter my lifestyle this time- high protein, more fat, less sugar and carbs…*

❖ Content Type

The purpose of looking into the type of message content exchanged within health-related OSGs was to determine if any of those contents seemed to evoke more disclosing of health information uses than other contents.

This coding schema was compiled from D'Alessandro, D'Alessandro and Colbert's (2000) list of health-related subjects found in unsolicited emails sent to physicians and White's (2000) expansion of Roter's (1984) content disease-related schema. Together these were chosen because they provide a broad list of the medical content issues that patients and health consumers deal with when discussing a diagnosis. The following table (Table 3.11) shows the sources from which the Content Type (CT) subcategories originated.

Table 3.11 Sources of Subcategories of the Content Type Coding Schema

Code Subcategory	Source
CT-01_Symptoms	(Roter, 1984)
CT-02_Differential_Diagnosis	(D'Alessandro et al., 2000) (Roter, 1984)
CT-03_Epidemiology	(Roter, 1984)
CT-04_Etiology	(Roter, 1984)
CT_05_Wellness (Health/Diet)	(Roter, 1984)
CT_06_Medication	(Roter, 1984)
CT-07_Diagnostic_Testing	(D'Alessandro et al., 2000)
CT-08_Pathophysiology	(D'Alessandro et al., 2000)
CT-09_Prognosis	(Roter, 1984)
CT-10_Treatment/Therapy	(D'Alessandro et al., 2000)
CT-11_NonMedical_Remarks	(Roter, 1984)

The following table (Table 3.12) shows definitions and examples from the data for each of the subcategories:

Table 3.12 Content Type Subcategories: Examples from Data

CT SUBCATEGORIES: DEFINITION AND EXAMPLES
Symptoms: Description of issues that person is having (For example: My symptoms seem to indicate that I could have a form of XXX or YYY)
Ex. I had AF type cramping into my second trimester. I honestly was terrified I was going to m/c because the cramps were so bad at times, but I now have a gorgeous 2-year old.
Differential_Diagnosis: The content of the post is about any aspect of a diagnosis other than the symptoms or the diagnosis itself, including examination process that leads to a diagnosis. (For example: We tried to conceive for more than a year with no results).
Ex. Well, I tried going to the ER. They told me I has kidney stones (*although they can't see any on the x-ray*). *Kidney Stones*!*!!! I can't believe it. I DON'T have kidney stones. So much for seeing things in a different light. I'll just wait until my appointment with my family doctor. Only one more week to go. This is why I always go so long with symptoms before going to the doctor.*
Epidemiology: The content of the post discusses incidence, prevalence, spread of disease, and morbidity & mortality. (For ex: Since my aunt was diagnosed with this condition, how likely is it that my kids or I could have it too?
Ex. I am a survivor of ovarian cancer; you can email me if you like. I was stage 4 surgery and treatment for 10 mos. The cancer spread to my lymph nodes also I was given meds before and after. Hope I can be of some assistance. I can maybe answer some of your questions.
Etiology: The content of the post talks about signs and studies related to determining the CAUSES of disease and their modes of expression. (For example: Is there any evidence that asbestosis can cause colon cancer?)
Ex. Hi, my name is IN-Thread21_seed I have stage 4 endo, I don't have my right ovary and I have no tubes. My endo is so severe that dh and I are going to doc to start ivf treatments in dec/jan. I have been on lupron and have had 5 laps done. I just wanted to tell ya'll a little bit of my story as I am fairly new here. .. P.S does anyone know if endo causes irritable bowel syndrome?
Wellness: The content of the post discusses issues of public health such as the effects of smoking, alcohol use, and physical activity on the condition. (For example: Has alcohol use been an issue in treating the condition?)
Ex. *I am on day 9 of the 2ww.....4th cycle. For the first 7 days I did minimal cardio. Yesterday was the first time I did weights. Do you think I should hold off on exercise/weights until I hear*?

Medication: The content of the post discusses how drugs are used to alleviate symptoms. (For example: Have you tried "X"?) *Ex. aspirin, heparin, folgard & progesterone*
Diagnostic_Testing: Content of the post is about describing any test performed with the purpose of aiding in the diagnosis of the condition. (For example: The doctor tested my PSA.) *Ex. I'm not sure if it's an issue but when they ran the fertility tests, I was not tested for either of those so I wonder what impact they really have if they didn't bother to check*?
Pathophysiology: When the content of the post is about the functional changes that accompany a particular syndrome or disease, in other words, a description of how the disease affects the body internally. This is different from symptom which refers to the signs people perceive about the disease. (For example: Increased protein breakdown and glucose production are some pathological abnormalities (pathophysiology) related to some cancers. A sign of these could be malnutrition.) *Ex. It supposedly gives the sperm a better chance of getting to the right place if you have a tipped uterus- they are closer to the entryway.*
Prognosis: The content of the post is about forecasting or predicting outcomes of the condition. (For example: How much more time will she get if she does treatment "X"?; What would be a ballpark figure of survival rates on people with my condition at this age?) *Ex. Everyone is different. However, I've done injectibles with IUI 3 times now and each time they monitored they said only follies which were 15+ would be considered mature enough to be a target egg. They do typically like to see the sizes closer together so that you have a few that will release an egg and increase your chances of getting pg. Just be careful that too many aren't mature because of the risk of high order multiples and OHSS.*
Treatment/Therapy: Post discusses different types of treatments or therapies other than medication, including diet, alternative treatment, physical therapy, surgical procedures, and types of treatments. (For example: Why do you think treatment "X" is the best option?) *Ex. I went on two round of clomid with induced periods with provera.*
NonMedical_Remarks: The post describes any content not specifically related to any of the previous medical subcategory aspects of a condition. *Ex. Thank you both for your answers. I hope I can continue if it's safe. The waiting kills me, you know*?

The selection of these coding schemas was based on what other researchers in the field have used, both because the schemas are well known and had worked well or because, as stated by MacLaren Chorney, McMurtry, Chambers and Bakeman's (2015), “It is not uncommon for researchers to find that there is no available coding scheme to address their research question, or that an existing coding scheme requires modification to fit their context” (p. 155). Thus, the schemas used here were improved, as necessary, by adjusting, adding, or deleting categories when they did not allow an adequate categorization of pieces of the unit of analysis. Other variables such as sex of the participant, diagnosed condition, the person who has the condition and the post number within the thread did not require a classification schema but were also coded as shown Table 3.13.

Table 3.13 Demographic Variables: Subcategories

Demographic Variables	**Code Values**
Diagnosed Condition	This will vary depending on the condition being studied
Sex of the participant	Sex_Male Sex_Female Sex_Unclear
Who has the condition?	Particip__has___condition
	Relationship_Spouse/Partner Relationship_ExtendedFamily Relationship_Friends&Others
	Particip_indicates_Nobody_has_condition

After the initial coding, the researcher revised the coding schemas based on intercoder reliability results and also as a result of looking at simple frequencies of each code category. If there were codes that were not assigned to any piece of a message, then those codes were dropped. Equally, if a miscellaneous code seemed to be used many times for several similar pieces of data, then a new code was added to that schema.

3.7. DATA COLLECTION

When trying to select an unobtrusive and naturalistic method to study online bulletin board conversations on any topic, the use of trace data can be a good alternative. As Nahl's (1997) states, the use of self-witnessing reports (such as bulletin board conversations) can be used to identify in an empirical way the range of information behaviors that can and do occur in the information environment on a routine basis.

For this research, which was trying to understand how the information provided within online health bulletin boards conversations was used, no other alternative would have been as unobtrusive and truthful regarding the information use behaviors of the participants in the context of their interactions other than looking at archived data. Sometimes this type of trace data may be the only data available for the study of certain problems.

Methodologically, another benefit to using trace data is that it provides opportunities for replication and longitudinal studies to be performed since the data is available over time. This research could be replicated as long as the sites maintain the archived data available.

Economically, it is usually cheaper to use existing data than to collect new data. When financial resources are scarce, this is an important and justifiable reason for choosing trace data, not to mention that it is a more convenient and less time-consuming data collection process than doing interviews or surveys, especially for health-related information.

Since the data used by the researcher was publicly available at the time of data collection, and as participants in online discussion boards are warned that the information they post can be used by third parties for purposes other than the one it was originally collected for, then the researcher did not seek permission from the participants to use the data. Nevertheless, the researcher took action to protect the privacy and confidentiality of the participants by removing any identifiable information (such as person's names, telephone numbers, SSN, web URLS, email addresses, references to street addresses, cities and states, and any other unique identifying code mentioned in the textual conversation) from the data that could in any way directly identify a participant (assuming that they provided their real name and/or email).

The de-identification of identifiable data was accomplished by changing nicknames used by participants in referring to others to a generic and unique identification code. Similar actions were taken with respect to mentions of email addresses, locations, phone numbers, and so on; a generic word identifying the data type was used to substitute for the identifiable data. For example, in the case of people posting their actual email address, the generic word 'email' was used as a substitute for that real data (See Table 3.14 for examples of de-identification substitutions).

Table 3.14 Examples of De-identification Substitution Values

Identifiable Word	Substitution Range of Values
Participant's nickname	OC-P001 … (ovarian cancer) PC-P001 … (prostate cancer) IN-P001 … (infertility)
Participant's email	email@ddress
Phone, fax, cell, or pager number	999–9999
Personal webpage address	Http://personal.website.address
Geographic information, including city, state, and zip code	Location_info

3.7.1. COMPONENTS OF THE SETTING

The settings from which the sample threads were collected varied between the life-threatening and non–life-threatening chronic conditions. The other consideration for the selection of the support groups was to include one discussion boards that affects each gender (prostate cancer, ovarian cancer) and one that affects both genders (infertility).

The online support group boards for the life-threatening chronic conditions (ovarian and prostate cancers) were very similar. In the ovarian cancer group, at the time of the data collection there were approximately 560 threads, of which approximately 13% were threads with no replies. For the prostate cancer group, the number of threads available at the time of the data collection was somewhat fewer than for the ovarian cancer group: approximately 460 threads, and similar to the ovarian group, the number of threads with no replies comprised about 10% of the data.

In the case of the infertility group, at the time of the data collection, there were approximately 1153 threads—twice as many as the ovarian or prostate groups—and the number of threads with no replies was about half the other groups, approximately 6% of the total.

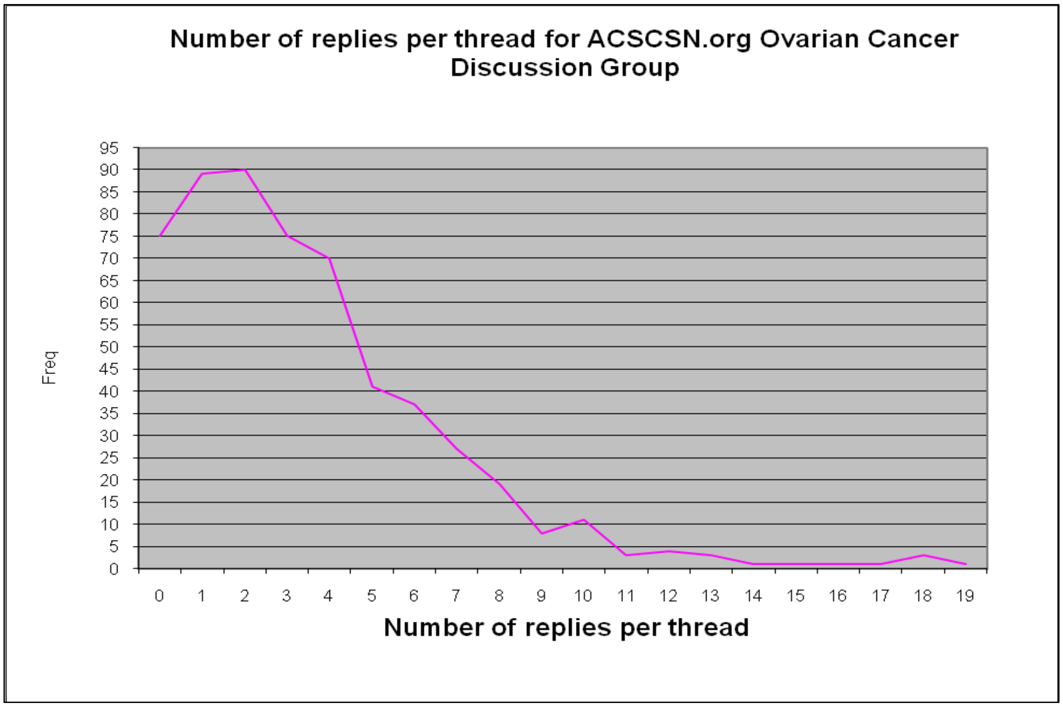

Figure 3.2 Example of a Power Law Distribution

All three of the support groups studied here followed a power law distribution, in which approximately 80% of the threads have few replies and 20% or less have lots of replies, as exemplified in Figure 3.2 above.

3.7.2. SELECTION OF SAMPLE MESSAGES

Once the support groups were chosen, the data collection process consisted of downloading and saving threads of messages from the different bulletin board archives following a systematic sampling procedure.

In this process, threads were evaluated to see that certain conditions were satisfied before proceeding with systematic sampling. In other words, for the first sampling unit to be selected it needed to satisfy some conditions; once it did, then the next Nth unit was evaluated and selected only if it also satisfied the conditions. If the Nth unit did not satisfy the conditions, then each following unit was evaluated until one that satisfied the conditions was found. The Nth unit varied from discussion board to discussion board. For the more active ones, every 10th unit was evaluated; others evaluated every 5th or every 3rd unit. This process was repeated until all necessary sampling units were collected. The rules for selection, referred to previously, include:

- ✓ No thread with 0 replies would be selected.

- ✓ No thread with more than 14 reply posts would be selected in order to make the analysis more manageable and understandable. This rule was based on an observation of the OSGs being studied that revealed that most threads seemed to have, at most, 10–14 replies. Those posts with more replies tended to have some 'topic drift.'[22] Longer threads usually occurred due to changes in the topic of the initial question (see example in Appendix H). Also, the longer the thread, the harder to understand the flow of the conversation and how the questions related to reported uses. Evidence of the effect of topic drift is supported by Sudau et al.'s (2014) study as well as that of Sharif, Ismail, Farooqi, Khan and Gulzar's (2015) research in which they suggest that topic drift is a very good indicator for

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[22] Topic drift: A tendency for the discussion to move to other, tangential subjects.

estimating how focused a conversation is, and it is often also suggestive of irrelevant content, or a possible diversion from the intended purpose of the conversation. Sharif et al.'s (2015) also reported finding “a visible increase in topic drift with the increasing number of responses” (p. 7).

- ✓ Thread initiator must reveal some information need by asking a question or inquiring about something from others members of the bulletin board community.

- ✓ Threads should include at least one reply comment from another member of the board and at least one feedback-providing or synthesizing response from the thread initiator to the other participants. This is as described by Kaye's (1992) as what is considered a true interaction.

- ✓ Each thread initiator can be selected only once for the sample.

The purpose of these conditions was to ensure that reciprocity was present in the threads, increasing the likelihood of finding information use instances to be analyzed.

3.7.3. SAMPLING SIZE

The decision regarding how much data needed to be collected was based on what other recent and related studies have used (Neuendorf, 2016) (see Table 3.15 below for details). In this case, 150 total threads of messages were collected (50 threads per each condition) which yielded 1,099 individual posts to be analyzed, falling within the range of what other researchers have selected about 3 to 15 posts per thread.

Table 3.15 Number of Units Analyzed in Related Research

Author	Paper Title	Health Condition Studied	Number of Postings Reviewed	Data Collection Period
White, M. D. (2000)	Questioning behavior on consumer health electronic lists	Colon Cancer	1000	2–3 months
Schoch, N. A. & White, D.M (1997)	A study of the communication patterns of participants in consumer health electronic SGs.	Diabetes & Colon cancer	1000 1000	2–3 months
Klemm,P., et al. (1998)	A nontraditional cancer support group: The Internet.	Colorectal cancer	300	9 days
Winzelberg, A. (1997)	The analysis of an electronic support group for individuals with eating disorders	Eating disorder	306	3 months
Weinberg, N., et al. (1996)	Cancer patients participate in a computer-mediated support group	Breast cancer	108 statements	3 months
White, M. & Dorman, S. (2000)	Online support for caregivers: Analysis of an Alzheimer group.	Alzheimer's	532	20 days
Klemm, P., et al. (1999)	Cyber solace: Gender differences on Internet cancer support groups.	Breast cancer, Prostate cancer, Mixed	945	45 days
Fox, J. (2014)	Case study of alopecia universalis and web-based news groups	Alopecia universalis	228 episodes	18 months
Preece, J. (1995)	Empathic communities: Reaching out across the web	Anterior cruciate ligaments	500	bi-monthly
Culver, J. D., et al. (1997)	Medical information on the Internet	Painful hand & arm condition	1658	5 months

3.7.4. UNITS

As described by (Neuendorf, 2016), in content analysis, units are any identifiable message or message component which can take the form of a word, sentence, paragraph, or theme, among others. Neuendorf's (2016) work also defines three different types of units: units of sampling, units of data collection, and units of analysis (described in Section 3.7.4.1, Section 3.7.4.2, and Section 3.10.1) and indicates that they are not always the same. In the next subsections, the researcher describes what data segments represent each of these units in this study.

3.7.4.1. UNIT OF SAMPLING

Unit of sampling refers to the units from the population that will be studied. In this case, the sampling units refer to each post.

3.7.4.2. UNIT OF DATA COLLECTION

When doing a content analysis and as suggested by Neuendorf's (2016), either or both of the unit of data collection and unit of analysis must be a message unit. For this research in particular, the unit of data collection refers to threads in CMC communications, which are composed of one or more messages/postings. The reason for choosing the thread as the unit of data collection was in order to preserve the context of the dialog which is supported by Chen, Lee, Chu, Wang and Jian's (2005) statement that "better insights into effective discussions[23] can be gained from a macro-view[24] of the threaded context" (p. 2). Other researchers, including Hill and Hughes's (1997) have also used threads as the unit of data collection when they determined that just looking at the individual posting would not provide all the context information needed.

The researcher selected threads with at least two replies, where one of these replies had to be from the threat initiator saying something to those who responded to his/her information inquiry. The decision for choosing only those postings with at least two replies was based on Neuendorf's (2016) suggestion that units should be large enough to well represent the phenomenon under investigation. The researcher considers that at least two replies to the original message are the minimum possible condition where information use instances could be observed, and thereby able to represent the phenomenon under investigation.

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[23] The term *effective discussion* is widely used but not clearly defined. According to some researchers, it seems to be used to characterize positive group learning or cognitive, on-topic, on-task, sustained learning processes. (Chen, Lee, Chu, Wang, & Jian, 2005)

[24] Macro-view refers to looking into a complete thread, including all its posts, so the context doesn't get lost.

3.8. DATA REDUCTION

As outlined by Miles and Huberman's (1994), "the process of data reduction[25] can be done even before the data is actually collected" (p. 10). They consider data reduction to be part of the analysis and a continuous process that starts when the researcher decides which research questions to use, what research methods to employ, what codes to employ, and which pieces of text will be coded and which will not.

For this research, one of the key elements in the data reduction process was development of the selection rules that were implemented. In other words, not all threads of posted messages could be randomly selected unless they satisfied some selection conditions. These rules (see Section 3.7.2) were implemented with the goal of collecting a more focused and sharpened data set, and they constitute a form data reduction.

3.9. COLLECTING THE DATA

One of the challenges in collecting the data was the availability of sites with bulletin boards related to the conditions chosen that did not restrict the use of the archived data for research purposes. Another issue with the data was the fact that several of the discussion boards were somewhat inactive, very few posts were available, and many of those posts contained

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[25] The process of selecting, focusing, abstracting, and transforming the data that appears in written field notes or transcriptions (Miles & Huberman, 1994).

two replies or fewer (even zero replies) to the original message; based on the conditions established for the selection, those threads were not a candidate for selection, restricting even further the number of available sample units.

To overcome those challenges in this work, the researcher focused the data search on open bulletin boards that anybody could access without requesting permission, which had no restrictions on the data itself, that were stable (the board had existed for a few years) and interactive (participants post to the forum frequently), and that conveyed a sense of membership (current members welcomed newcomers and offered support) (McEwan, 2016).

Collecting the data from the archives, as opposed to surveying or interviewing, had the advantage that capturing possible occurrences of information use as they were described by the discussion board participants was possible without affecting what they might say if they knew their conversations were being studied. At the same time, using archived data has the disadvantage that if the participants did not express how they used the information they received, the researcher could not ask them how or why.

Besides these pros and cons, there is the added difficulty of privacy and HIPAA regulations when it comes to doing research on health-related issues.

Using publicly available archived data was less restrictive for the researcher and a good way to deal with the challenge of accessing health-related information.

3.10. DATA ANALYSIS

This research sought to address what kinds of information use behaviors were being disclosed in online health support groups as related to participants' characteristics as well as how message characteristics related to the information use behaviors disclosed by participants according to the message content, the types of questions asked, and the functions of the reply messages.

First, a qualitative content analysis review of the message pool data was performed by two coders using improved a priori coding schemas to describe the data in terms of: (a) demographic variables, (b) information use behaviors disclosed by the participants; (c) the health-related message content, (d) types of questions asked in relation to the information uses; and (e) the functions of the reply messages. The quantitative portion of the analysis consisted of using some descriptive and analytical statistical measures, including frequency distributions and chi-square analysis testing of independence followed by and some cross-tabulation among variables, to capture important patterns within the data.

Once the data was collected, the analytical framework described by (Miles & Huberman, 1994) was applied. The steps for the application of this framework or 'ladder of analytical abstraction' called for "(1) creating the texts to work on and trying out coding categories, (2) identifying themes and trends in the data, and (3) integrating the data into an explanatory framework by doing matrix analysis of major themes" (p. 92).

Following the ladder up, the researcher converted each thread of bulletin board (BB) conversations into plain text format, as required by the software to be used for coding. Each thread file was saved with a unique name indicating from which site the data came from and a sequential number (for ex. "(FertileThoughts) BB Thread N-17.txt"). Inside the thread there were all the posts related to it, each assigned with a unique name indicating which condition they belong to, as well as a participant number for within the thread (for ex. "IN-Thread04_seed, IN-Thread04_02"). Then, the coding process started by using the a priori coding schemas selected (for details on the selection of the schemas see Section 3.6). The following figure (Figure 3.3) shows the process of coding each post for each of the different coding schemas (demographics, Function of Reply Messages, health-related Content Type, and Question Type).

Each of the variables in Table 3.13 was coded for each post within each sampled thread. No information learned within one thread was carried out to the next thread. Within a thread, the information about gender was kept consistent for each poster even if this datum was presented only once. Each post was coded by gender, by a unique identifying code, by who has condition issues, by as many different function of reply messages were described, and by as many different medical contents were discussed. For each question asked, and for each description of an information use, a sentence was used as the unit of analysis. Once all different variables were coded then in order to analyze the findings with respect to the presence of information use instances with the other variables then we look at the whole thread as an aggregate, meaning re-reading the question asked and re-reading the replies with possible IUs to decide if that response was indeed an information use to be associated with the question that was asked, the function of the message and the content type

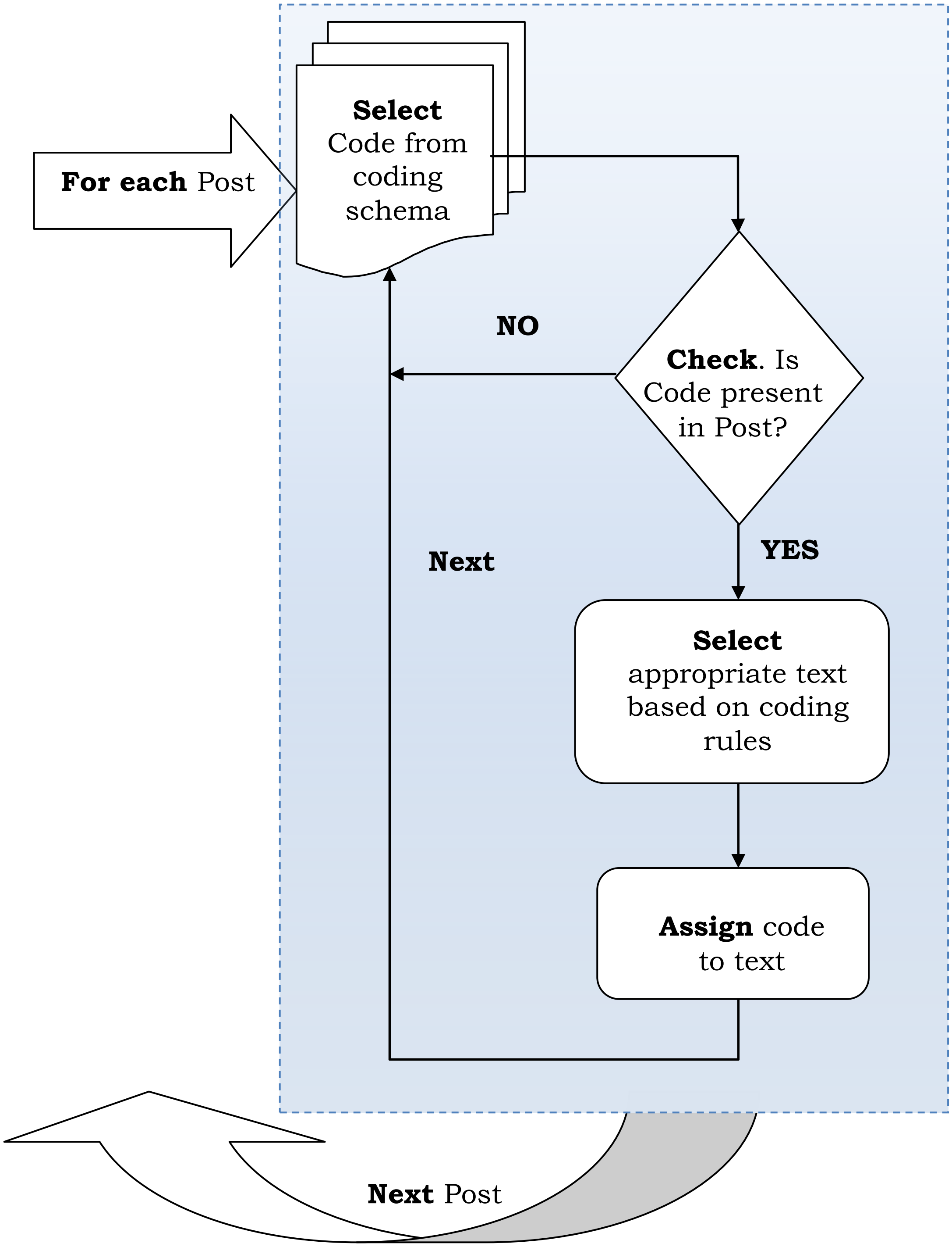


Figure 3.3 Data Coding Process using the

The next step consisted of evaluating the coded data to look for relationships among categories. This process was done by using some of the ATLAS.ti query capabilities. Once all the possible computations were done and cross-tabulation matrices were created, then the last step required was trying to see patterns in the data through description or through the development of an explanatory framework (Bradley, 1993; Neuendorf, 2016).

Even though the application of both qualitative and quantitative methods for the analysis of data is not a very common triangulation method (Miles & Huberman, 1994; Neuendorf, 2016), it is still used. Thus, it was used for this research as well, not only because it is supported in the literature, but also because, as pointed out by Gray and Densten's (1998), it “strengthens researcher’s claims for the validity of conclusions drawn” which gives the research the strength of both qualitative and quantitative (p. 420) analysis methods.

3.10.1. UNIT OF ANALYSIS

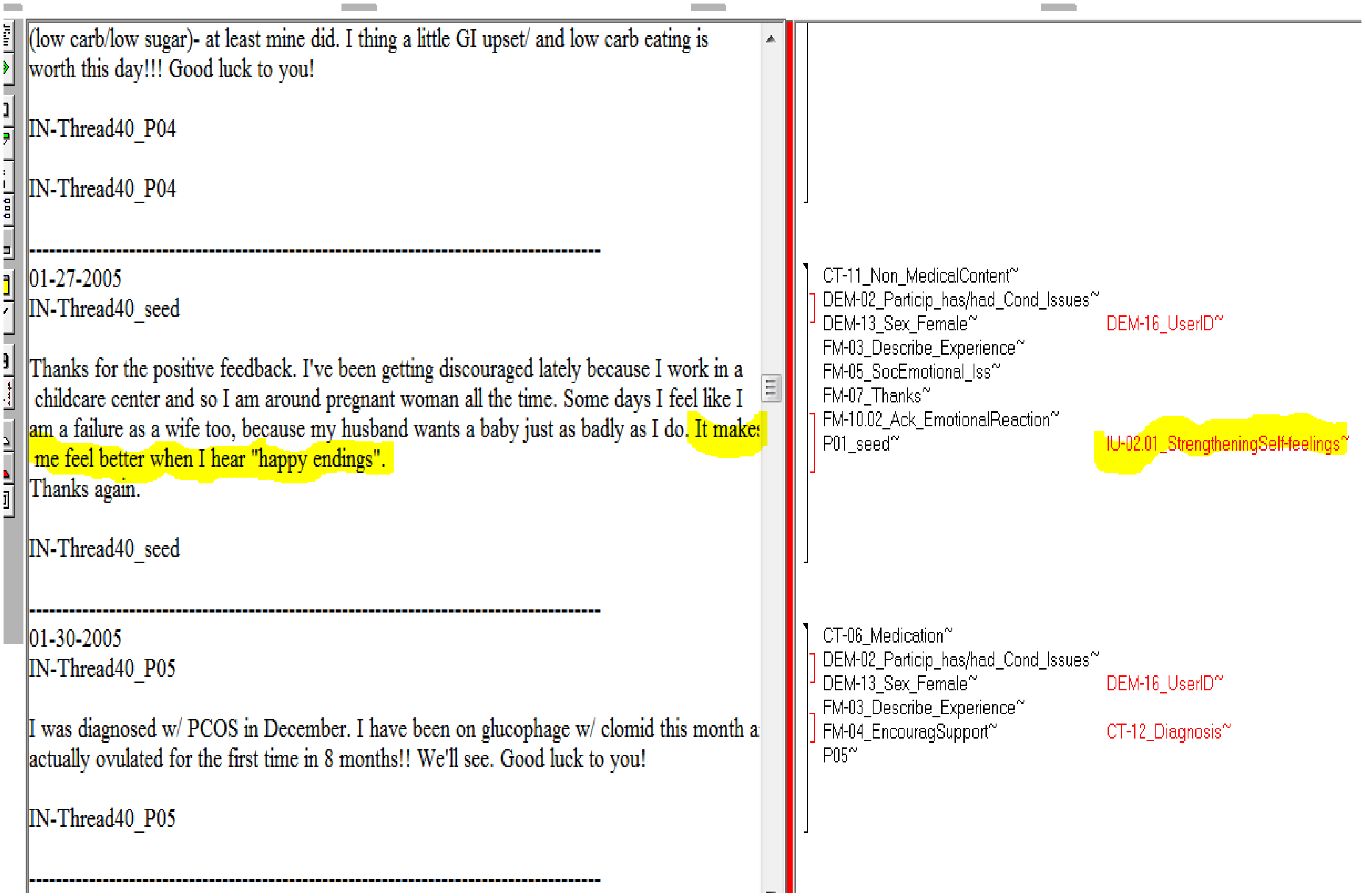
The unit of analysis, as indicated by Neuendorf's (2016), refers to the elements on which data is analyzed and for which findings are reported. Thus, after looking into the pros and cons of selecting a sentence, a paragraph, or a unit of meaning, it was decided that there would be different units of analysis for different parts of the coding schemas. This decision helped make the process of data segmentation clearer and less prone to intercoder disagreements and, in the long run, supports consistency and validity of the coding schema as argued by Pfeil and Zaphiris's (2010). No exclusion criteria based on gender, place of origin, or native language of the sender was applied to filter messages.

For most of the variables, the complete post was used as the unit of analysis and for the rest either a sentence or a question was used as shown below in Table 3.16.

Table 3.16 Rules for Coding Each Unit of Analysis

Variable	Selection for Coding
Username	Name only
Unique Identifying code	Complete post
Sex	Complete post
Who has Condition issues?	Complete post
Function of reply messages	Complete post
Disease-related message content	Complete post
Diagnosis	Sentence
Information Use	Sentence
Type of question asked	Question

A thread sample from this study data can be seen in Figure 3.4 below.



(low carb/low sugar)- at least mine did. I thing a little GI upset/ and low carb eating is worth this day!!! Good luck to you!

IN-Thread40_P04

IN-Thread40_P04

01-27-2005
IN-Thread40_seed

Thanks for the positive feedback. I've been getting discouraged lately because I work in a childcare center and so I am around pregnant woman all the time. Some days I feel like I am a failure as a wife too, because my husband wants a baby just as badly as I do. It make
me feel better when I hear "happy endings".
Thanks again.

IN-Thread40_seed

01-30-2005
IN-Thread40_P05

I was diagnosed w/ PCOS in December. I have been on glucophage w/ clomid this month a
actually ovulated for the first time in 8 months!! We'll see. Good luck to you!

IN-Thread40_P05

CT-11_Non_MedicalContent~
DEM-02_Particip_has/had_Cond_Issues~
DEM-13_Sex_Female~
FM-03_Describe_Experience~
FM-05_SocEmotional_Iss~
FM-07_Thanks~
FM-10.02_Ack_EmotionalReaction~
P01_seed~
DEM-16_UserID~
IU-02.01_StrengtheningSelf-feelings~

CT-06_Medication~
DEM-02_Particip_has/had_Cond_Issues~
DEM-13_Sex_Female~
FM-03_Describe_Experience~
FM-04_EncouragSupport~
P05~
DEM-16_UserID~
CT-12_Diagnosis~

Figure 3.4 Thread Sample with an Information Use Unit of Analysis Highlighted

While coding each post, multiple codes could be assigned, in more than one category or along more than one dimension. This multi-functionality coding as Folger, Hewes and Poole's (1984) put it, allows for a more accurate characterization of the text. Then, once all data was coded, the researcher used the ATLAS.ti query tool and Microsoft Excel spreadsheets to look for and establish meaningful patterns of behavior within the data.

To select the size of the sample to be studied, the researcher looked at what similar studies had used. Several of these researchers studied around 1000 units (see Table 3.15 for details) which, in their cases, referred to single posts. Since the unit of data collection for this research refers to threads, which contain around seven posts on average, then the equivalent number of observations were around 150 thread units, which in this case yielded 1,097 individual posts.

3.10.2. DATA ANALYSIS SOFTWARE

For the qualitative part of the analysis, the researcher selected the qualitative data analysis software called ATLAS.ti 4.2. This software allowed the researcher to code and view different levels of data (sentence, phrase, or paragraph) for each post within each thread of the bulletin board conversations, using a predefined list of codes created by the researcher from the coding schemas selected for the study. The software also facilitated uncovering some of the complex phenomena hidden in the data by making connections among codes through the use of queries, relationships among families of codes, and through the frequency of codes used.

In addition, the researcher used Microsoft Excel for Windows in order to do some cross-tabulation of major variables to model and explore relationships between them and also to compute some basic descriptive statistics about the data.

3.10.3. ANALYSIS OF PILOT DATA

After deciding on the size of the pilot data (18 bulletin board threads) and selecting a set containing units from each of the three different data sources, one set was selected to be processed by two coders (the researcher and another person). The researcher explained the general purpose of the study to the second coder and they did some coding together as a training method and familiarize the second coder with the coding schemas before coding independently. During the coding process, the coding disagreements that occur were dealt with through discussion between the coders until a consensus was reached. The changes made to the coding schemas, where they originated as well as examples of each of the subcategories were described in Sections 3.5, 3.6, and 3.7. Once all the pilot data was coded, an intercoder reliability test was performed to determine the accuracy of the coding schemas and to clarify and specify the coding categories, their definitions, and examples.

3.10.4. INTERCODER RELIABILITY TEST

Despite that there is no consensus on what statistics are better to measure intercoder reliability or the reproducibility of a coding schema, Krippendorff's (1980) indicates that there are several measures available for this purpose. This research applied some commonly used measures as described by Miles and Huberman's (1994) and (Neuendorf, 2016), such as Cohen's kappa, and the percentage agreement coefficient. Cohen's Kappa is a statistic that allows measuring inter-judge agreement for nominal scales other than by chance:

$$\text{Cohen's kappa} = \frac{PA_O - PA_E}{1 - PA_E}$$

"Where PA_O stands for "proportion agreement, observed," A the number of agreements between the two coders, and n_A and n_B are the number of units coded by coders A and B, respectively" (Neuendorf, 2016, p. 176-177).

$$PA_E = 2A/(n_A + n_B)$$

"Where PA_E stands for proportion agreement, expected by chance," (Neuendorf, 2016, p. 177) which is the same reliability formula described by Miles and Huberman's (1994).

The percentage agreement coefficient is defined as the proportion of the number of classification decisions that were in agreement compared to the total number of decisions made:

$$\text{Reliability} = \frac{\text{number of agreements}}{\text{number of agreements + disagreements}}$$

(Miles & Huberman, 1994)

Using the percentage agreement coefficient, the values obtained for each of the categories in Table 3.17 below were very similar to those from the Cohen's kappa values.

Table 3.17 Percentage Agreement Coefficient Reliability Scores of Each Major Subcategory

Reliability Scores Using	% Agreement Coefficient
%Coef_ContetType=	**93%**
%Coef_FunctionOfMessage=	**84%**
%Coef_InformationUses=	**88%**
%Coef_QuestionType=	**95%**
%Coef_Demographics=	**100%**

In general, as pointed out by (Neuendorf, 2016), reliability coefficients above 80% would be acceptable in most situations but below that, there exists great disagreement.

Once all the coding was done by both coders independently, then the percentage agreement coefficient was computed for each of the four different coding schemas as well as for the basic demographic type data. Since most of these scores in the initial run of the coding were below what is generally agreed in the literature as an acceptable level of reliability (Neuendorf, 2016), a further review of the coding schemas was done.

This review determined that part of the disagreement between the coders was due to the failure of either the coder or the researcher to see a codifiable element in the selected unit. Another reason for disagreement was due to the fact that the distinction between some codes was vague, so it was sometimes difficult to decide which code was more appropriate and that tended to cause disagreements. Hence, those codes needed to be collapsed and redefined into broader categories, and their definitions needed to be more concisely detailed for the disagreements to diminish. All differences in coding were negotiated until a consensus was reached.

The results of the initial intercoder reliability test for each of the coding schemas, based on Miles and Huberman's (1994) formula, are as follows (see Table 3.18 below):

Table 3.18 Results of First Intercoder Reliability Test

Cohen's Kappa	% Agreement
K_ContentType=	**72%**
K_FunctionOfMessage=	**73%**
K_InformationUses=	**63%**
K_QuestionTypes=	**65%**
K_Demographics=	**92%**

After all changes in the coding schemas were performed, the data was re-coded by the two coders to solve their coding disagreements. Then new intercoder reliability scores for each of the coding schemas was calculated using Scott's pi, to assess the agreement between the raters as shown in Table 3.19 (these scores are based on about 12% of the sample).

Table 3.19 Results of Final Intercoder Reliability Test

Cohen's Kappa	% Agreement
K_ContentTypes =	**96%**
K_FunctionOfMessages=	**90%**
K_InformationUses=	**92%**
K_QuestionTypes=	**97%**
K_Demographics=	**100%**

Once all the percentage agreements reached acceptable levels, a complete set of data was coded by the principal researcher alone.

3.11. METHODOLOGICAL CHALLENGES

As pointed out by several researchers (Frankfort-Nachmias & Nachmias, 1996; Katzer, Cook, & Crouch, 1998; Fleisher, Bauerle Bass, Burt Ruzek, & McKeown-Conn, 2002; Neuendorf, 2016), no validated instruments currently exist to measure how information from the Internet is used or, in this case, how consumer health information from Internet support groups is used. Thus, for this reason, this study employed a series of classification schemes adapted from several other researchers that related to the idea of measuring the effect of using information within the online environment through the observation of naturally occurring online health discussions.

3.11.1. SOURCES OF BIAS

There are several possible sources of error that can be inadvertently introduced into any research study, all of which need to be addressed by the researcher in order to avoid compromising the quality of the research in progress. These sources of error can be either systematic or random. Systematic errors as described by Katzer et al.'s (1998) work are bias, which occurs always in the same direction and is the result of some specific source (e.g., the researcher, the methodology used, the participant, the coders). Random or nonsystematic errors, on the other hand, are noise, which as described by Katzer et al. (1998), can have unpredictable directions and sometimes can be large and other times small.

It is important to point out that, as stated by Katzer's (1987), “Some research plans are more susceptible to biased distortions than others and that even though it is impossible to eliminate all of them, an adequate concern for research design was eliminate the major ones” (p. 60). Thus, in the next section, the biases that affected this research are mentioned, and the steps the researcher took to minimize their effect are described.

3.11.1.1. RESEARCHER BIASES

Since the source of data for this investigation is archived information, the researcher bias due to interaction with subjects is null. Instead, the researcher, as a source of bias, can be due to her choice of research design, choice of coding schemas, and her expectations in terms of the desired outcome of the study. Thus, in order for the researcher to minimize these potential sources of bias, initial thoughts on both issues were discussed with committee members, and proper adjustments to the coding schemas and research design were made. The choice of research design was based on what other investigators have done in similar research. Care in controlling the reliability of the study was incorporated as part of the research plan.

3.11.1.2. METHODOLOGY BIASES

Some of the possible methodological biases that could affect this research include: bias due to sampling and coverage bias.

The sampling technique chosen for this study (random sampling) in itself helped the researcher to minimize bias, as opposed to other sampling techniques, such purposive sampling, for example, where subject self-selection can play a major bias role. What might cause some bias with the sampling technique here is the set of rules for selection of the sample that were implemented, in that some potential cases of information use instances not considered by the researcher could be excluded from the sample. The researcher set up these rules (See Section 3.7.2 for explanation of the rules for selection) to allow for the inclusion of the most possible cases where the information use instances might occur, because considering the whole population by doing random sampling alone would yield too much unusable data.

There is also a possible bias from what participants choose to report about, either because of convenience, because some types of behaviors might be easier to recall than other, or because of a cultural bias.

Some people might expect that because this study is looking only at information use instances by those board participants that actually made posts, that there is some form of participant self-selection coverage bias[26] present here, but since what the researcher is interested in is precisely the information use behaviors of those who purposely asked questions, then the nonactive participants do not belong to the population of interest and so no coverage bias by participants' indirect self-exclusion was present here. This view of active posters vs. lurkers is supported by research findings from Van Uden-Kraan et al.'s (2008); Mo and Coulson's (2010) who indicated that "active posters are significantly more likely to report that they have received useful information or support from the group" (p. 198) and hence report greater psychological well-being and better stigma recovery than lurkers.

3.11.1.3. CODER BIASES

One likely source of bias for this research can be introduced by the coders' expectations of the research or by their interpretation of unclear coding instructions. In order to minimize the effect of this form of coder bias, the researcher gave the only other coder beside herself minimal explanations in terms of the purpose and goals of the research to avoid forming a predetermined notion of what the investigator might want to observe in the results. Coding instructions, which included a description of each codifiable unit, and instructions on the coding protocol were given to

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[26] Coverage bias related to Internet research occurs when some members of a population are not included in a sample, in this case because of choosing not to participate in the online board discussions.

the coder prior to starting the coding process so she could become familiar with the codes and ask questions about those that seemed ambiguous. The instructions were then tested with a few threads. Unclear code descriptions were modified when there was some confusion. Preliminary modifications to the coding schema were also made to resolve ambiguities in terms of whether or not to use information learned about a discussion board participant in a previous section of the thread or from other threads and whether to code all variables for same poster each time the poster appeared or only the variables that were different.

CHAPTER SUMMARY

This chapter has outlined assumptions, the rationale for using archived data, and the content analysis technique, sampling technique, data collection process, challenges, limitations, and overall research design.

The goal of this study was to develop a better understanding of how health consumers are actually using information they receive within online support groups in response to questions they ask. In order to reach that goal, the study used a combination of qualitative methods, such as content analysis of archived data, with some quantitative statistics to process and to analyze the data. It is important to notice that as Fiksdal et al. (2014) said, “The overarching goal of qualitative research is to explore and describe particularities of a social phenomenon rather than producing generalizable results” (p. 9).

The methodological challenges and sources of biases were identified, and potential ways to reduce their effect were proposed. In addition, the criteria used to evaluate the quality and the measures proposed to increase the quality of the study were presented.

As a final point, a pilot analysis of a subset of the data was presented and intercoder reliability statistics were computed to determine the reliability of the coding schemas.

CHAPTER 4: FINDINGS

4.1. INTRODUCTION

This purpose of this chapter is to report on the study findings in connection with the research questions. In order to achieve the study's aim, which was to gain some understanding of how consumers use health information obtained from online support groups, the researcher embarked in an exploratory and descriptive investigation about online health information use behaviors.

Given the exploratory and descriptive nature of the study, the results were reported here mainly thorough basic statistics, and descriptive summaries which provided a snapshop of how the sample data participants relate their online health information uses to other peers in the support group. The research was guided by the following specific research questions:

RQ1: What types of information use behaviors are disclosed in online health support groups according to participants' characteristics?

RQ2: How do message characteristics relate to the information use behaviors disclosed by participants?

4.2. DISTRIBUTION OF DEMOGRAPHICS IN THE SAMPLE

This research looked into 150 threads of online health discussion group conversations, out of which 1,099 total individual posts were found. Within those individual posts and across all the conditions, there were about 11% of posters who did not specify the individual who had the condition issues, but the vast majority (about 73%) reported they themselves had the condition issues, and about 16% of the posts were by those participants who presented themselves as being a relative or a friend of a person with condition issues (spouse/partner, and parent relationships were the more frequently reported at 56% and 27%, respectively).

Of the total number of individual posts, there were 689 unique participants (249 in OC group, 227 in PC group and 213 in IN group).

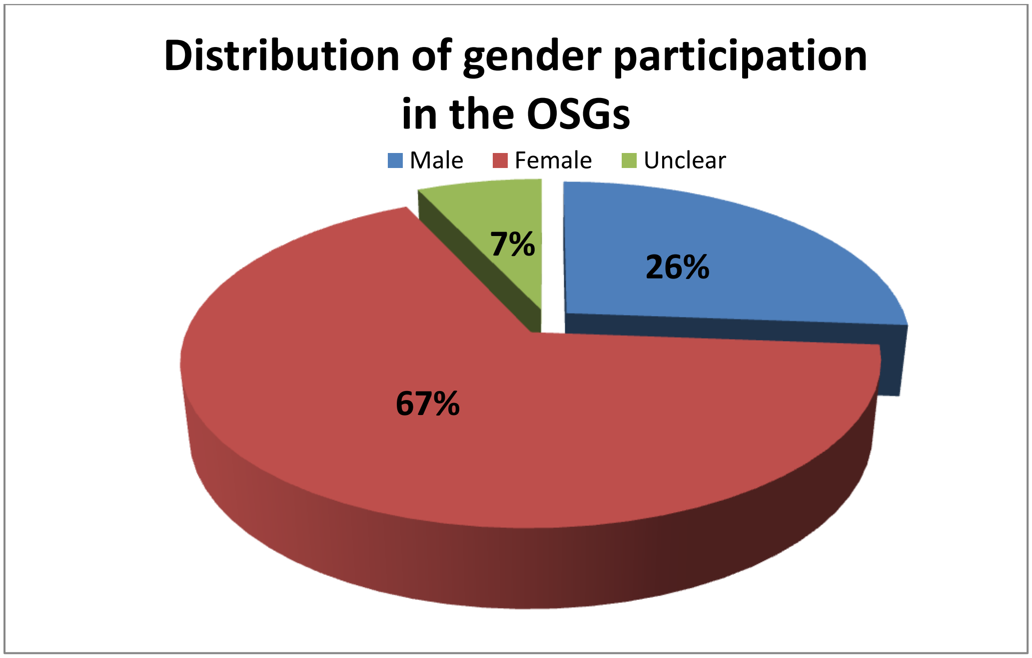

Figure 4.1 Distribution of Gender Participation in the OSGs

In terms of overall numbers of males and females participating from the OSGs, this research data showed that there were 734 female participants (67%), 288 male participants (26%), and 77 participants where the gender was unclear (7%).

More specifically, when looking into each of the discussion groups (prostate cancer, ovarian cancer and infertility), the researcher found that the distribution of who had the condition issues compared to those seeking support for others was similar in proportion in each group.

In the prostate group, about 71% of the participants indicated that they themselves have or had the conditions issues and about 18% indicated that a friend or family had them. Similarly, in the ovarian group, 74% indicated that they have or had the condition issues and only 13% were about family or friends with the condition. In the infertility group, about 74% had the condition issues and about 16% said a family or friend had them.

The groups differed in the relative proportion of the relationship of the family/friend for which the information was intended. Within the prostate and infertility groups, when participants were there on behalf of somebody else, the relationship with the highest proportion was for spouse/partner followed by that of extended family.

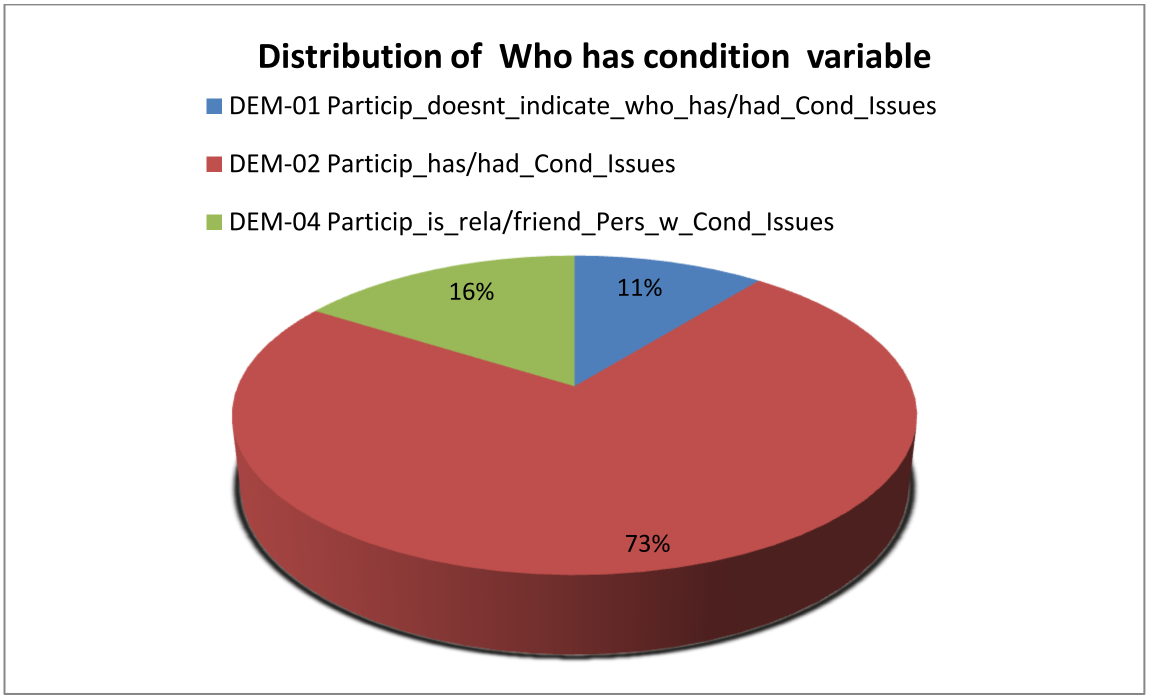

Figure 4.2 Distribution of Demographics About Who Has Condition for all OSGs

Table 4.1 Distribution of Demographic Codes by Online Support Groups

	Online Support Groups					
	Ovarian		Prostate		Infertility	
Demographic codes (DEM)	n	%	n	%	n	%
Particip_doesnt_indicate_who_has/had_CondIssues	48	13%	35	10%	37	11%
Particip_has/had_Cond_Issues	277	73%	248	70%	273	73%
Particip_indicates_Nobody_has_Cond_Issues	0		2	1%	0	
Particip_is_rela/friend_Pers_w_Cond_Issues	52	14%	67	19%	60	16%
Totals	**377**	**100%**	**352**	**100%**	**370**	100%

In terms of gender information, it was very noticeable that male participation in the support groups for ovarian cancer and infertility was very low or nonexistent (about 2% and less), which doesn't mean men are not affected by infertility, but in the sites studied, they were not very involved in the support groups. Female participation in the prostate group was, on the other hand, more visible (around 12%), which supports the results of (Fox & Rainee, 2000) that: "Men are more likely to look for support about their own condition whereas women seek support for themselves and on behalf of parents and other relatives" (p. 7).

We could not apply a Chi Square test to table 4.1 as it is because the subcategory about participants indicating Nobody has condition issues had a frequency below threshold. Applying a Chi Square test using the remaining categories gives us a p-test value of 0.27, thus telling us the variable who has condition issues is independent of the health conditions.

Table 4.2 Distribution of Demographics Codes in the Ovarian group

	Ovarian Cancer Discussion Group						
	Male		**Female**		**Unclear**		
Demographic Codes (DEM)	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**	**Totals**
Particip_doesnt_indicate_who_has/had_CondIssues	4	8%	34	71%	10	21%	**48**
Particip_has/had_Cond_Issues	0	0%	277	100%	0	0%	**277**
Particip_indicates_Nobody_has_Cond_Issues	0		0		0		**0**
Particip_is_rela/friend_Pers_w_Cond_Issues	5	10%	28	54%	19	37%	**52**
Totals	**9**	**2%**	**339**	**90%**	**29**	**8%**	**377**

After excluding the subcategory about participants indicating Nobody has condition issues for table 4.2 due to a low frequency, a Chi Square test gave us a p-value of 2.72E-26 which is well below the widely-accepted threshold of 0.05. This p score tells us with a high degree of confidence that there is a significant relationship between gender and the Who has conditions issues in the Ovarian group. For example, if participants indicate they have or have had condition issues then their expected gender is Female.

Table 4.3 Distribution of Demographics Codes in the Infertility Group

	Infertility Discussion Group						
	Male		**Female**		**Unclear**		**Totals**
Demographic Codes (DEM)	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**	
Particip_doesnt_indicate_who_has/had_CondIssues	0	0%	29	78%	8	22%	**37**
Particip_has/had_Cond_Issues	3	1%	266	97%	4	1%	**273**
Particip_indicates_Nobody_has_Cond_Issues	0		0		0		**0**
Particip_is_rela/friend_Pers_w_Cond_Issues	0	0%	58	97%	2	3%	**60**
Totals	**3**	**1%**	**353**	**95%**	**14**	**4%**	**370**

After excluding the subcategory about participants indicating Nobody has condition issues for table 4.3 due to a low frequency, a Chi-Square test reveals a significant p-value=1.53E-07, meaning there is a significant relationship between who has condition issues and gender in the infertility group. Within the infertility group, whether the participant indicates that itself or a relative has condition issues or doesn't indicate it at all, the gender reported is overwhelmingly female.

Table 4.4 Distribution of Demographics Codes in the Prostate Group

	Prostate Cancer Discussion Group						
	Male		Female		Unclear		Totals
Demographic Codes (DEM)	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**	
Particip_doesnt_indicate_who_has/had_CondIssues	16	46%	0	0%	19	54%	**35**
Particip_has/had_Cond_Issues	248	100%	0	0%	0	0%	**248**
Particip_indicates_Nobody_has_Cond_Issues	1	50%	0	0%	1	50%	**2**
Particip_is_rela/friend_Pers_w_Cond_Issues	11	16%	42	63%	14	21%	**67**
Totals	**276**	**78%**	**42**	**12%**	**34**	**10%**	**352**

Initially, we did not apply a Chi Square test to table 4.4 because the subcategory Particip_indicates_Nobody_has_Cond_Issue had low frequency below threshold of 5. Once we excluded this group, a Chi Square test revealed a significant p-value=1.08E-71 meaning a relationship between who has condition issues and gender was identified in the prostate group. Indeed, when participants indicated they have or have had the condition, their identified gender was male.

4.3. INTERPRETATION OF THE FINDINGS

The following diagram represents an interaction process among peers within an online SG. The trigger is the thread initiator question followed by an *n* number of reciprocal interaction feedback messages between participants of the OSG. The result response may display a cognitive, an affective, or a behavioral action; it may provide acknowledgement of the usefulness of the feedback received or may show a feedback message with no indication of whether the information was used or not.

In order to analyze the coded data, we created a sort of “report card” for the thread detailing all the Content type codes, Function of reply messages codes, all the Questions types codes and all the Information use codes that were assigned within that thread, how many of each and which codes co-occurred. For example, in the IN thread #3,

(2) QT-20 were asked ----→ and they co-occurred with IU-03.04

(1) FM-07 ----------|

(1) FM-10.03 ------| -----→ they co-occurred with IU-03.04

(1) CT-11 ----------|

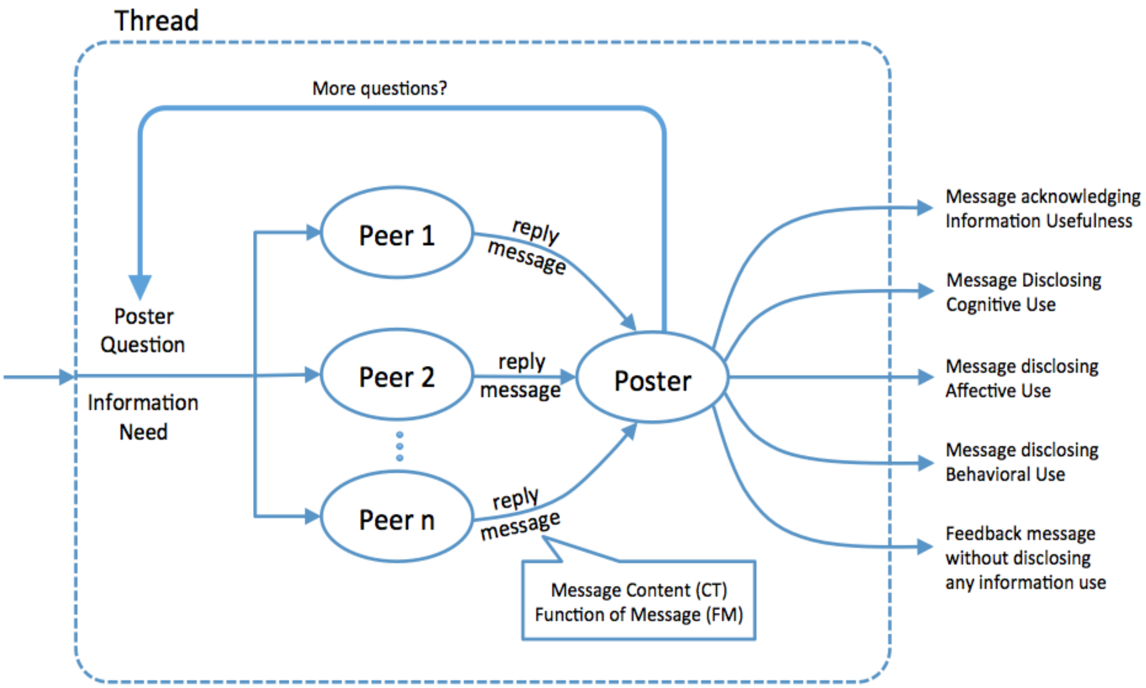

Figure 4.3 Interaction within OSGs and types of IU outcomes

4.3.1. ASSESSING THE MEANING OF THE HEALTH INFORMATION USE BEHAVIORS DISCLOSED BY PARTICIPANTS IN OSGS (RQ1)

When looking at the three categories of information use in this study: cognitive, affective, and behavioral reactions, and looking across the three chronic health conditions being researched (ovarian cancer, prostate cancer and infertility), the data showed that of those who reported information uses, 18% indicated changes in their cognitive behavior, 26% described changes in their affective behavior, and more than half (56%) implied behavioral action taken as a result of information exchanged within the online support group in which they participated.

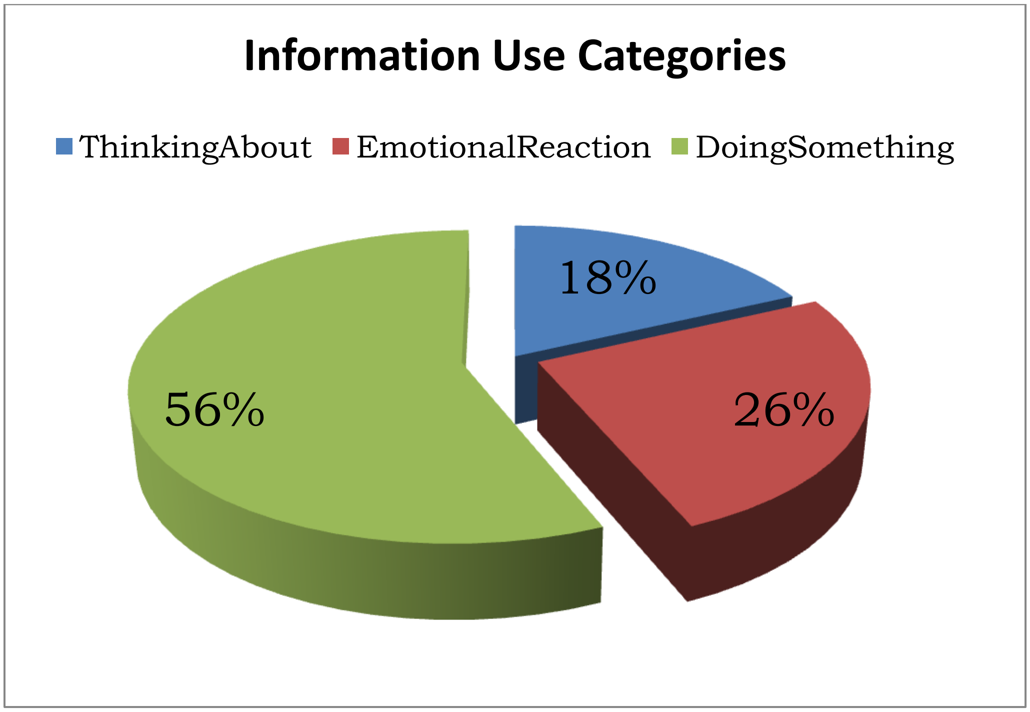

Figure 4.4 Distribution of Information Use Categories Across all OSGs

More specifically, looking into each discussion group separately, they all showed very similar proportions over the whole sample in that the most frequently described use category referred to the Behavioral IUs, followed by Affective IU, and lastly, Cognitive IU.

Table 4.5 Frequencies of Information Use Categories by Online Support Groups. Chi-square p-test of 0.9509 not significant with Alpha level of .05

Information Use Categories	Online Support Groups						Totals	
	Ovarian C.		Prostate C.		Infertility			
	n	%	n	%	n	%	n	%
Cognitive IUs	6	15%	8	20%	10	18%	**24**	**18%**
Affective IUs	9	23%	10	26%	15	27%	**34**	**26%**
Behavioral IUs	23	62%	21	54%	31	55%	**75**	**56%**
Totals	38	100%	39	100%	56	100%	**133**	100%

There were no reports of information use from males within the ovarian and infertility groups, but there were, indeed, female reports of information use within the prostate group.

In the infertility group, female participants were the only ones that revealed information uses. Of those information uses, 55% were about Behavioral IUs, 27% referred to Affective IUs and 18% to Cognitive IUs. In the prostate group, 54% of the IUs were Behavioral IUs and 26% of were about Affective IUs. In the ovarian group, 62% of the IUs were about Behavioral IUs and 23% about Affective IUs. For all the online SGs the cognitive IUs were 20% or less.

Comparing the tallies of the information use categories and the online support groups using a chi-square test, we learn that these variables are independent with a high degree of confidence (a 0.9509 probability). Thus, there is no significant relationship between the type of online support group and the cognitive, affective or behavioral information uses.

In the following sections the specific findings for each of the sub-questions of RQ1 will be described.

RQ1a: ***What specific cognitive information use behaviors were disclosed?***

Cognitive information use behaviors refer to any direct reference to changes in a person's thoughts or understanding as a direct result of the application of information (Todd, 1999b; Nahl, 2001), in this case, that was received from online support groups.

Initially this category was defined by a set of ten subcategories (New RealisticPict, NewGeneralUnderstanding, SeeRoadAhead, IdentifyPossibilities, LearningManageStress, LearningAvoidPitfalls, GettingMoreConfused, HowInfoIsInterpreted, BecomingWilling2Talk, and TakingActiveRole). After the data analysis was performed, several categories that had zero points across all conditions were consolidated or eliminated so that the final set consists of only six subcategories. These subcategories represented the cognitive information use behaviors that were more frequently adopted by the participants across the three support groups selected for the study.

The data here (see Table 4.6 below) shows that overall, participants from across the three conditions felt the information shared in the online support group helped them to identify possibilities (38%), to gain new and improved understanding about their situation (29%) and to learn how to avoid pitfalls (21%). The other subcategories which included LearningManageStress, HowInfoIsInterpreted, and GettingBetterInformed each equally represented just 4% of the total number of reported cognitive health information uses. The following chart shows the distribution of this data in the Cognitive Information Use category.

Table 4.6 Frequencies of Cognitive IUs Subcategories by OSG

	Ovarian		Prostate		Infertility		Totals	
Cognitive IUs	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
IU-01.01_NewImprovedUnderstanding	1	17%	5	63%	1	10%	**7**	**29%**
IU-01.02_IdentifyingPossibilities	3	50%	**2**	25%	4	40%	**9**	**38%**
IU-01.03_LearningManageStress	0	0%	**0**	0%	1	10%	**1**	**4%**
IU-01.04_LearningAvoidPitfalls	0	0%	**1**	13%	4	40%	**5**	**21%**
IU-01.05_HowInfoIsInterpreted	1	17%	**0**	0%	0	0%	**1**	**4%**
IU-01.06_GettingBetterInformed	1	17%	**0**	0%	0	0%	**1**	**4%**
Totals	6	100%	**8**	100%	10	100%	**24**	100%

Looking into each of the conditions, the data shows that participants in the ovarian group used the information mainly for IdentifyingPossibilities (50%), and equally for NewImprovedUnderstanding (17%), HowInfoIs Interpreted (17%), and GettingBetterInformed (17%).

Within the prostate group, the main cognitive use was to gain a NewImprovedUnderstanding (63%), followed by IdentifyingPossibilities (25%) and LearningAvoidPitfalls (13%). Lastly, in the infertility group, participants' main cognitive use was equally divided between IdentifyingPossibilities and LearningAvoidPitfalls with 40% each.

The chi-square test could not be applied to the data on this table as the test requires total frequencies of at least five occurrences. If we eliminate the information use categories with frequencies less than five, a chi-square test gives us a p-test of 0.091 meaning that these variables are independent. However, since the frequencies are low and the p value is low, it is still possible that aggregating the data an actual relationship exists.

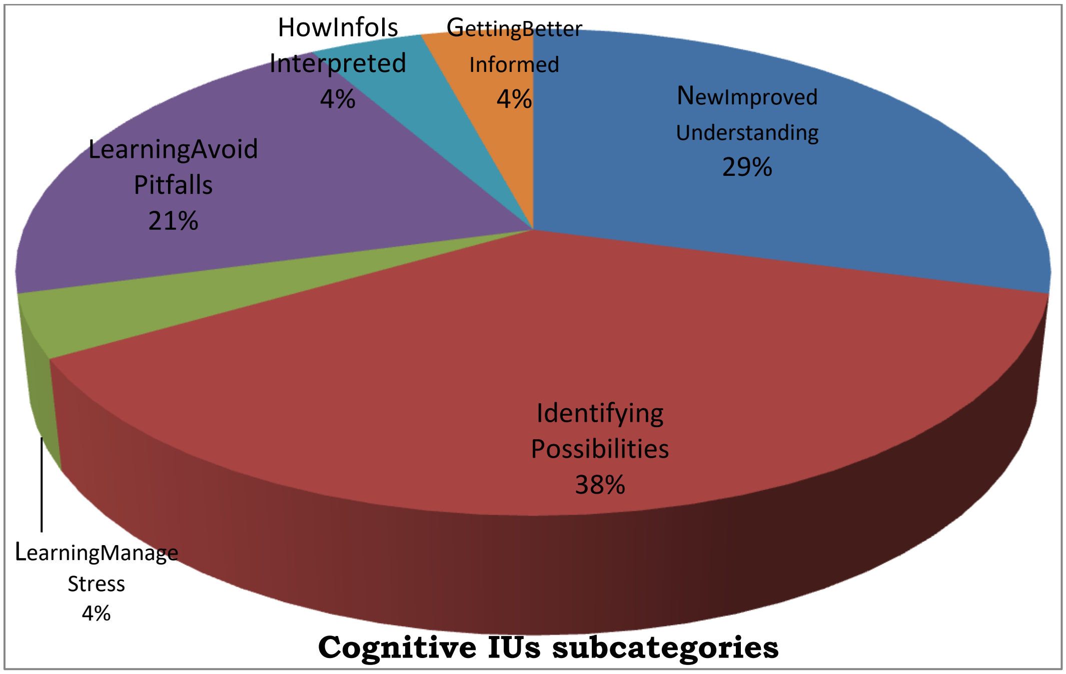

Figure 4.5 Distribution of Cognitive Information Uses Across all OSGs

RQ1b: *What specific affective information use behaviors were disclosed?*

Affective information use behaviors refer to any direct reference to expression of feelings experienced or affect as a direct result of the application of information received (Dervin, 1992; Nahl, 2001), in this case, from online support groups.

At first, this category was defined by a set of nine subcategories: (IncrOrDecrFeelings, ResistantToNewInfo, IncrDecrFeelings, StrengthenSelf-feelings, GotMotivated2TakeAction, BetterAble2Relax, FeelingConected2

_Others, FeelingLessIsolated, Able2CopeWithLoss, ReliefUnwanted Responsab). After the data analysis was performed, several categories that have zero points across all conditions were eliminated, resulting in four subcategories to define the AffectiveIU category (see Appendix C for a complete definition of coding schema subcategories).

Table 4.7 Frequencies of Affective IUs Subcategories by OSGs

Affective IUs	Ovarian		Prostate		Infertility		Totals	
	n	%	n	%	n	%	n	%
IU-02.01_StrengtheningSelf-feelings	3	33%	2	20%	3	20%	**8**	**24%**
IU-02.03_BetterAble2Relax	1	11%	0	0%	0	0%	**1**	**3%**
IU-02.04_FeelingConnected2_Others	4	44%	3	30%	9	60%	**16**	**47%**
IU-02.05_IncrDecrFeelings	1	11%	5	50%	3	20%	**9**	**26%**
Totals	9	100%	10	100	15	100%	**34**	**100%**

These subcategories represented the affective information use behaviors that were more frequently disclosed by the participants across the three support groups selected for the study. The most reported affective behavior was FeelingConnected2_Others (47%), followed by IncrDecrFeelings (26%), StrengtheningSelf-Feelings (24%), and BetterAble2Relax (3%).

Within the ovarian group the most prevalent feeling expressed as result of using information shared was FeelingConnected20thers (44%), followed by StrengtheningSelf-feelings (33%). For the prostate group, the main affective category expressed was IncrDecrFeelings (50%), followed by

Feeling_ Connected2_ Others (30%). Lastly, within the infertility group, the main disclosed affective category was also Feeling Connected2 _Others (60%), followed by StrengtheningSelf-feelings and IncrDecrFeeling (each at 20%).

A chi-square test could not be applied to the data in the table as the BetterAble2Relax category has a frequency of one, which is less than the minimum frequency of five required to apply the test. Ignoring this category, a chi-square test produced a p-test value of 0.318 leading as to conclude that the two variables in the table are independent. That is, the type of support group does not determine the types of affective IUs reported. Nevertheless, since the p value is low and the data frequencies are also low, it is still possible that aggregating the data a relationship can exists.

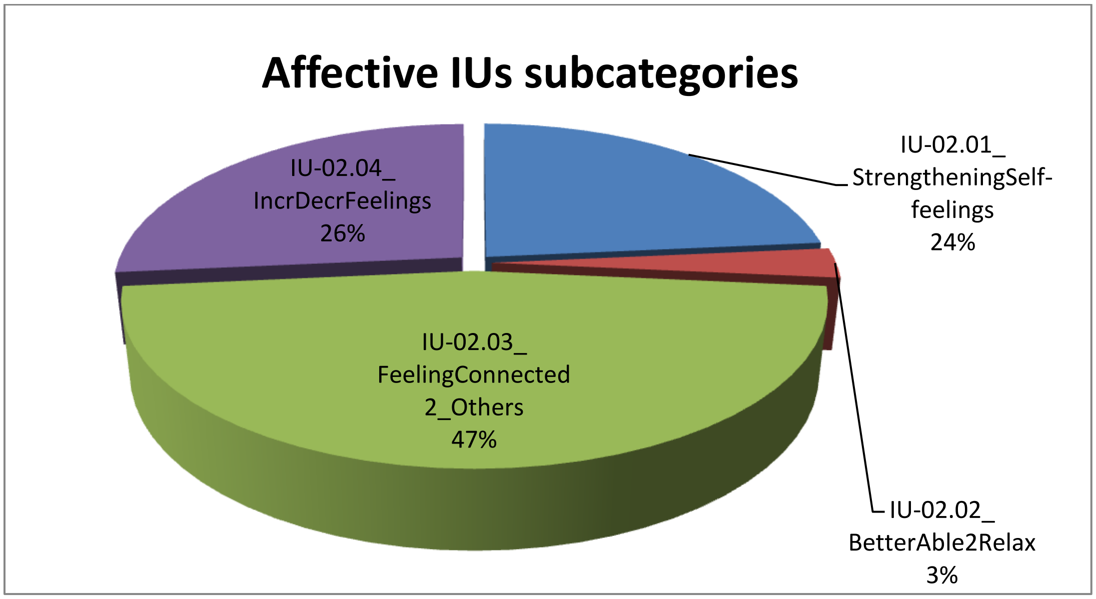

Figure 4.6 Distribution of Affective Information Uses Across all OSGs

RQ1c: *What specific behavioral information use actions were disclosed?*

Behavioral information use actions refer to any direct reference to acting in specific ways, and physical changes in end-states, impacts, practice, and procedures as a direct result of the application of information received (Todd, 1999b; Nahl, 2001), in this case, from online support groups.

The Behavioral IUs category was initially defined by a set of nine subcategories (TookInformedDecision, RequestedCopyMedRecords, Requested2ndOpinion, SelfMedicating, TakingMoreActiveRole, Advocate AboutCondition, TookActionBasedOnSuggest, TalkingAboutCondition, MakingChangesInLifeStyle). After the data analysis was completed, several categories with zero points across all conditions were eliminated, ending with the following five subcategories listed in table 4.8 (see Appendix C for a complete description of coding schema subcategories).

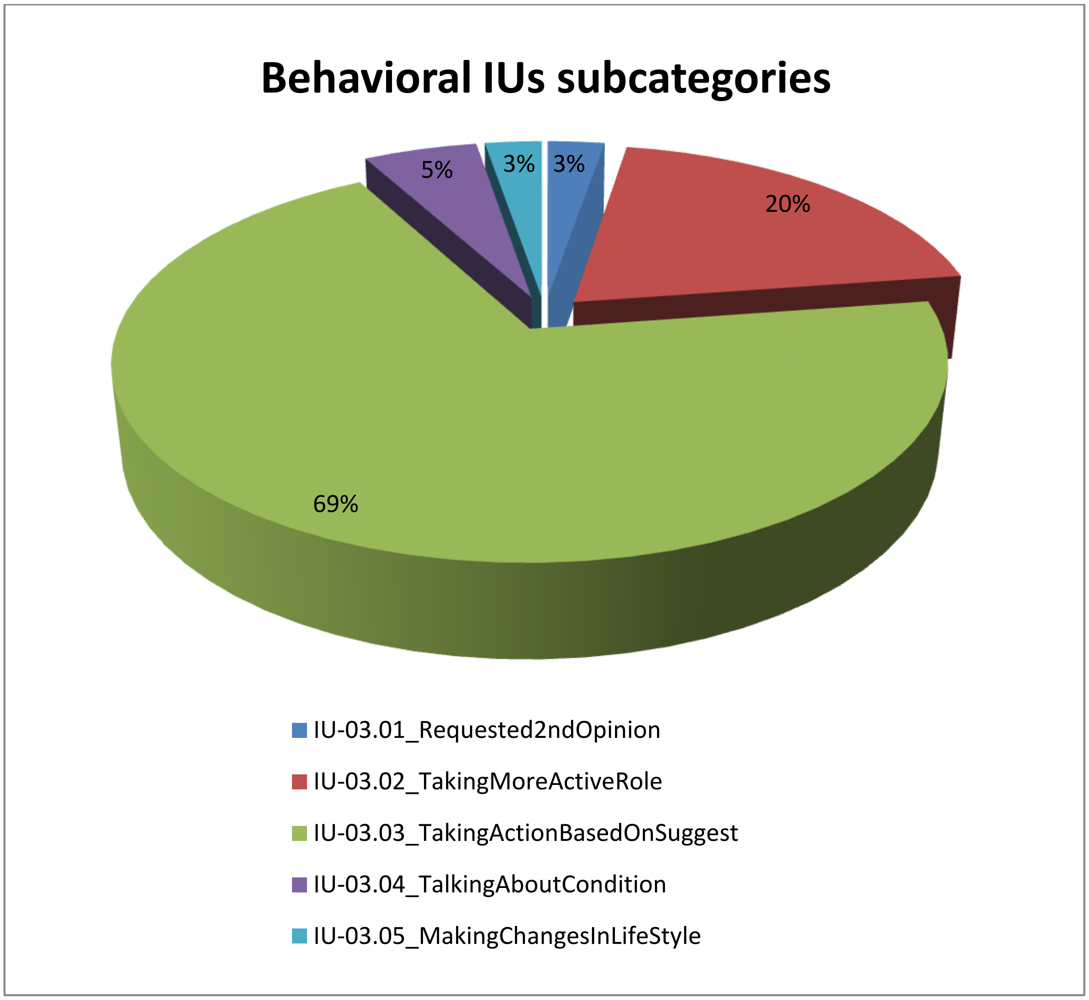

Figure 4.7 Distribution of Behavioral Information Uses Across all OSGs

These subcategories represented the behavioral actions that were more frequently reported by the participants as being adopted across the three support groups selected for the study. Among all subcategories, Taking ActionBasedOnSuggest was overwhelmingly the most popular action reported (69%), followed by TakingMoreActiveRole (20%) and Talking AboutCondition (5%). MakingChangesInLifeStyle (3%) and Requested 2ndOpinion (3%) both had the same volume of participation.

Table 4.8 Frequencies of Behavioral IU Subcategories by OSGs

	Ovarian		Prostate		Infertility		Totals	
Behavioral IUs	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**
IU-03.01_Requested2ndOpinion	0	0%	1	5%	1	3%	**2**	**3%**
IU-03.02_TakingMoreActiveRole	7	30%	6	29%	2	6%	**15**	**20%**
IU-03.03_TakingActionBasedOnSuggest	16	70%	13	62%	23	74%	**52**	**69%**
IU-03.04_TalkingAboutCondition	0	0%	1	5%	3	10%	**4**	**5%**
IU-03.05_MakingChangesInLifeStyle	0	0%	0	0%	2	6%	**2**	**3%**
Totals	**23**	100%	**21**	100%	**31**	100%	**75**	100%

Looking more specifically within each of the groups being studied, we found that, for all three groups, the most frequently reported BehavioralIU subcategory was TakingActionBasedOnSuggest with the ovarian group showing a 70% occurrence, the prostate group showing a 62% occurrence, and the infertility group displaying a 74% occurrence. The second most reported action in the cancer groups was TakingMoreActiveRole: in the ovarian group, its occurrence was 30% and in the prostate group it was 29%. Within the Infertility group, the second most reported BehavioralIU subcategory was TalkingAboutCondition at 10%.

A chi-square test could not be performed on this table because some of the information use tallies are less than the required minimum of five occurrences. Removing the rows with frequencies less than five, a chi-square test gives us a p-test value of 0.117. Hence, we have to conclude that the Behavioral information use is independent of the type of online support group. However, since the p value is low and the data frequencies are also low, it is still possible that aggregating the data a relationship can exists.

4.3.2. ASSESSING HOW MESSAGE CHARACTERISTICS RELATE TO THE INFORMATION USE BEHAVIORS DISCLOSED BY PARTICIPANTS (RQ2)

The second research question tested whether those information behaviors disclosed in RQ1 showed any association with the message characteristics of content, question type, or the function of the reply messages.

2a: In terms of health-related message content (CT)?
2b: In terms of the functions of the reply messages (FM)?
2c: In terms of types of questions asked (QT)?

For each of these variables (CT, FM & QT), the frequency count reported in each table refer to the number of post reported per each specific subcategory in all the data set.

2a: Type of health-related message content (CT):

Looking into the disease-related content results alone, we can see how the different content type subcategories change across the different chronic life-threatening and chronic non–life-threatening diseases.

Within the ovarian cancer discussion group, the most frequently discussed content types were Medication (23%) and Treatment/Therapy (22%), followed by NonMedical_Remarks (21%). Diagnostic_Testing also occurred frequently (17%) as compared with all other subcategories.

Table 4.9 Distribution of Content Type by the OSGs

	Ovarian n= 644		**Prostate n= 606**		**Infertility n= 584**	
Content Type Codes (CT)	**n**	**%**	**n**	**%**	**n**	**%**
CT-01_Symptoms	59	9%	12	2%	39	7%
CT-02_Differential_Diagnosis	10	2%	0	0%	11	2%
CT-03_Epidemiology	3	0%	1	0%	0	0%
CT-04_Etiology	7	1%	1	0%	5	1%
CT-05_Wellness	0	0%	0	0%	3	1%
CT-06_Medication	147	23%	93	15%	136	23%
CT-07_Diagnostic_Testing	108	17%	145	24%	103	18%
CT-08_Pathophysiology	14	2%	12	2%	5	1%
CT-09_Prognosis	19	3%	11	2%	33	6%
CT-10_Treatment/Therapy	139	22%	179	30%	128	22%
CT-11_NonMedical_Remarks	138	21%	152	25%	121	21%

The most frequently discussed content type within the prostate group was Treatment/Theraphy (30%) followed by NonMedical_Remarks (25%), Diagnostic _Testing (24%), and Medication (15%). In the infertility group, the most frequently reported category was Medication (23%), followed by Treatment/Therapy (22%), NonMedical_ Remarks (21%), and Diagnostic_ Testing (18%).

It is remarkable to see how the results for the ovarian group and the infertility group are almost identical in terms of the content types that were more relevant in both conditions. A chi-square test cannot be done on the data of this table as there are rows with frequencies less than five occurrences, which is the minimum required to apply the test. Ignoring the low-frequency rows in order to apply the chi-square test, we get a p-test value of 5.40E-13, which is well below the accepted confidence value of 0.05. This indicates that the content type is not independent of the type of online of support group, but that, in fact, there is a relationship. That is, the observed results are not by chance, but influenced by the type of health condition. For the Prostate group, there is less Symptoms (CT-01) and less Medication (CT-06); more Diagnostic testing (CT-07) and Treatment (CT-10).

In all three groups, about 60% of the posts evenly contain discussions related to medications being taken (CT06), treatment (CT_10), and diagnostic testing (CT_07), another 12% of the posts are about prognosis (CT_09) and symptoms (CT_01), and most of the remaining portion (about 25% of the total) consists of posts containing non medical remarks.

This seems to suggest that about three-quarters of posts deal mainly with pragmatic aspects of each health condition: tests people had to determine their current health condition, their symptoms, medications and treatments they are following, as well as the likely course of their condition.

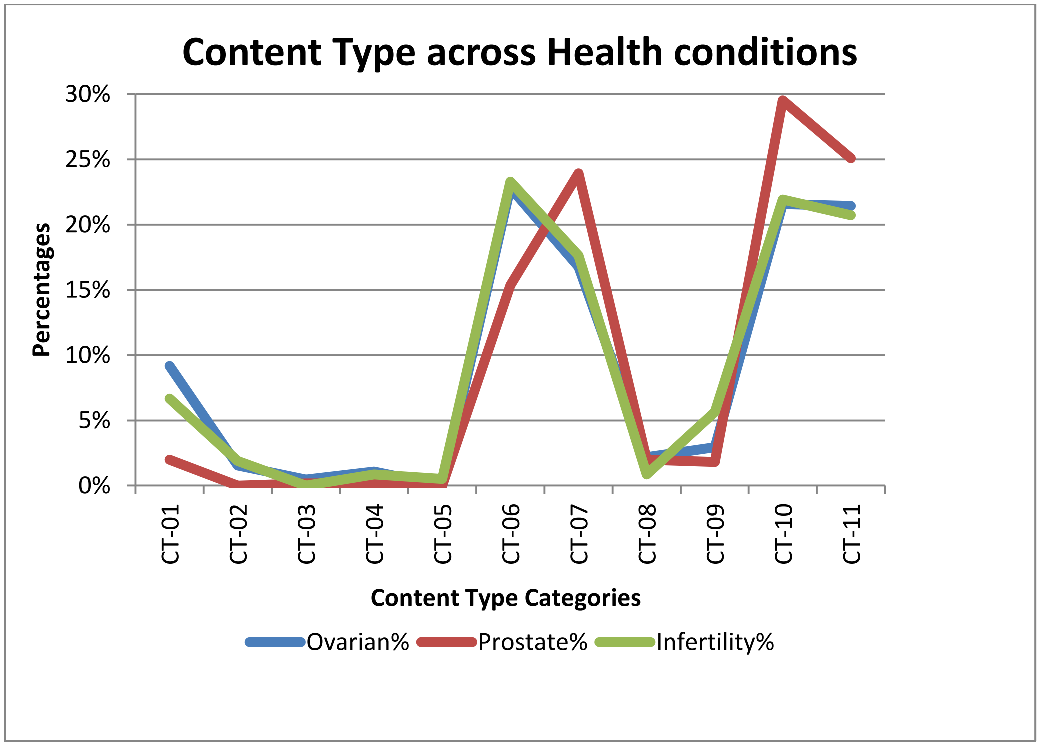

Figure 4.8 Distribution of Content Type across health conditions

There was very little or no incidences related to how it was determined which condition someone had (CT_02), the causes or reasons for having a given health condition (CT_04) or its relation to the population at large (CT03) or personal wellness.

The following tables looked into how the Content Type category and the three categories of information use relate to each other within the three conditions.

Cognitive Information Use by Content Type categories

Examining the relationships between the cognitive subcategories and the Content Type subcategories the data shows some small co-occurrences between IdentifyingPossibilities and Treatment/Therapy, as well as between NewImprovedUnderstanding and both Treatment/Therapy and NonMedical_Remarks (see Appendix C for complete coding schemas).

Cognitive IUs Subcategories
IU-01.01_NewImprovedUnderstanding
IU-01.02_IdentifyingPossibilities
IU-01.03_LearningManageStress
IU-01.04_LearningAvoidPitfalls
IU-01.05_HowInfoIsInterpreted
IU-01.06_GettingBetterInformed

Table 4.10 Distribution of Cognitive IUs by Content Type Subcategories

	Cognitive IUs						
Content Type Codes (CT)	**IU-01.01**	**IU-01.02**	**IU-01.03**	**IU-01.04**	**IU-01.05**	**IU-01.06**	**Totals**
CT-01_Symptoms	1	0	0	0	0	1	**2**
CT-02_Differential_Diagnosis	1	0	0	0	0	1	**2**
CT-06_Medication	1	2	1	1	0	0	**5**
CT-07_Diagnostic_Testing	1	2	0	0	0	1	**4**
CT-09_Prognosis	0	1	0	0	0	0	**1**
CT-10_Treatment/Therapy	4	5	1	2	0	1	**13**
CT-11_NonMedical_Remarks	3	2	1	2	0	0	**8**
Totals	**11**	**12**	**3**	**5**	**0**	**4**	**35**

The frequencies in the table above are too low to apply a chi-square test. Applying the chi-square test on the categories with five or more occurrences gives a p-test value of 0.934, which points to a high probability that the Cognitive information use type and the Content Type of the messages are independent.

Affective Information Uses by Content Type Categories

Within the Affective subcategories and the Content Type subcategories it was found that the subcategories with the highest co-occurrences were FeelingConnected20thers with NonMedical_Remarks, StrengtheningSelf-feelings with IncrDecrFeeling and also with NonMedical _Remarks. These were followed by FeelingConnected20thers and IncrDecrFeelings with Diagnostic_Testing and Medication. Lastly, some interaction was observed between StrengtheningSelf-feelings and DiagnosticTesting and Medication.

Affective IUs subcategories
IU-02.01_StrengtheningSelf-feelings
IU-02.02_GettingMotivated2TakeAction
IU-02.03_BetterAble2Relax
IU-02.04_FeelingConnected20thers
IU-02.05_IncrDecrFeelings

Table 4.11 Distribution of Affective IUs by Content Type Category

	Affective IUs subcategories					
Content Type Codes (CT)	**IU-02.01**	**IU-02.02**	**IU-02.03**	**IU-02.04**	**IU-02.05**	**Totals**
CT-01_Symptoms	1	0	0	0	0	**1**
CT-02_Differential_Diagnosis	1	0	0	0	0	**1**
CT-06_Medication	2	0	0	4	4	**10**
CT-07_Diagnostic_Testing	3	0	0	4	4	**11**
CT-09_Prognosis	1	0	0	0	1	**2**
CT-10_Treatment/Therapy	0	0	0	0	4	**4**
CT-11_NonMedical_Remarks	6	0	1	13	6	**26**
Totals	**14**	**0**	**1**	**21**	**19**	**55**

A chi-square test cannot be applied to the data in the table because of the presence of low-frequency tallies. Applying a chi-square test on the subset of categories with sufficient occurrences gives a p-test value of 0.872, potentially indicating that Affective information uses reported in the posts are independent of the Content Type of the post.

Behavioral Information Uses by Content Type Categories

Within these categories, it was found that the subcategories that reported the highest frequency of co-occurrence were TakingAction BasedOnSuggest with NonMedical_Remarks, with Treatment_ Therapy, with Medication and with Diagnostic_Testing. The next pairs showing some correlation were TakingMoreActiveRole with Treatment_Therapy, with

NonMedica1_Remarks, and with Diagnostic_Testing (see Appendix C for a complete description of coding schema subcategories).

Behavioral IUs subcategories
IU-03.01_Requested2ndOpinion
IU-03.02_TakingMoreActiveRole
IU-03.03_TakingActionBasedOnSuggest
IU-03.04_TalkingAboutCondition
IU-03.05_MakingChangesInLifeStyle

Table 4.12 Distribution of Behavioral IUs by Content Type Category

	Behavioral IUs					
Content Type Codes (CT)	**IU-03.01**	**IU-03.02**	**IU-03.03**	**IU-03.04**	**IU-03.05**	**Totals**
CT-01_Symptoms	0	2	5	0	0	**7**
CT-02_Differential_Diagnosis	0	1	3	0	0	**4**
CT-06_Medication	2	3	12	0	1	**18**
CT-07_Diagnostic_Testing	0	6	11	0	0	**17**
CT-09_Prognosis	0	1	0	0	0	**1**
CT-10_Treatment/Therapy	2	7	16	1	2	**28**
CT-11_NonMedical_Remarks	1	7	27	3	1	**39**
Totals	**5**	**27**	**74**	**4**	**4**	**114**

After excluding the CT-09_Prognosis category due to low frequency, a chi-square test resulted in a p-test value of 0.91, which strongly indicates that the Behavioral information uses reported are independent of the Content Type of the post. In other words, the type of content of a post does not determine which behavioral information use appears.

Aggregated table for Information Uses by Content Type

The table below aggregates the specific information uses with respect to content types into the columns Cognitive, Affective, and Behavioral from Tables 4.10, 4.11 and 4.12 respectively.

Table 4.13 Distribution Content Type by Information Uses

	Cognitive IUs n= 32		Affective IUs n= 52		Behavioral IUs n= 107	
Content Type Codes (CT)	**N**	**%**	**n**	**%**	**n**	**%**
CT-01_Symptoms	2	6%	1	2%	7	6%
CT-06_Medication	5	16%	10	19%	18	17%
CT-07_Diagnostic_Testing	4	13%	11	21%	17	16%
CT-10_Treatment/Therapy	13	41%	4	8%	28	26%
CT-11_NonMedical_Remarks	8	25%	26	50%	39	36%

A Chi Square test yields a p-value of 0.025, which is below the widely accepted confidence threshold of 0.05 thus indicating a significant relationship between the Content Type and the Information Uses categories. Looking at differences of at least 5%, we can see that for diagnostic testing there are less incidences of cognitive information uses; for treatment there is less affective and more cognitive information uses; and for posting containing non-medical remarks there are more incidences of affective information uses, and less of cognitive information uses.

2b: The Function of Reply Messages (FM):

Looking into the function of the reply messages results alone, we can see that for most of the subcategories, there is little change across them for the different chronic life-threatening and chronic non–life threatening conditions.

Table 4.14 Distribution of Function of Reply Messages by OSG

	Ovarian		Prostate		Infertility	
Function of Reply Messages (FM)	**n**	**%**	**n**	**%**	**n**	**%**
FM-01_Info_Seeking	125	13%	111	13%	106	14%
FM-02_Info_Giving	155	16%	177	21%	154	20%
FM-03_Describe_Experience	248	25%	217	25%	177	23%
FM-04_EncouragSupport	149	15%	132	15%	140	18%
FM-05_SocEmotional_Iss	78	8%	34	4%	42	5%
FM-06_Humor	10	1%	11	1%	7	1%
FM-07_Thanks	76	8%	79	9%	81	10%
FM-08_Prayer	117	12%	49	6%	24	3%
FM-09_Ack_InfoUsefulness	6	1%	1	0%	5	1%
FM-10.01_Ack_CognitiveIU	7	1%	7	1%	9	1%
FM-10.02_Ack_AffectiveIU	8	1%	10	1%	10	1%
FM-10.03_Ack_BehavioralIU	19	2%	20	2%	25	3%
FM-11_Ack_NonInfoUse	0	0%	0	0%	1	0%
FM-12_TechBoard_Iss	0	0%	4	0%	1	0%
FM-13_Miscellaneous_Comment	0	0%	6	1%	3	0%
Totals	998		858		785	

We found that across all three conditions, Describe_Experience was the most frequent Function of Reply Messages reported (around 24%), followed by Info_Giving (about 18%), EncouragSupport (16%), and Info_Seeking (around 13%) (see Appendix C for a complete description of coding schema subcategories).

More specifically, within the ovarian group, the most frequent Function of Reply Message (FM) was Describe_Experience (25%), followed by Info_Giving (16%), and EncouragSupport (15%). Info_Seeking (13%) and Prayer (12%) round up the top five subcategories. For the prostate group, the most frequent FM was Describe_Experience (25%), followed by Info_Giving (21%). EncouragSupport (15%), and Info_Seeking (13%). Similarly, in the infertility_group, the most frequent Function of Reply Message (FM) was Describe_ Experience (23%), followed by Info_Giving (20%), EncouragSupport (18%), and Info_Seeking (14%).

This distribution of the Function of Reply Message categories is very unlikely to be the result of random sampling, and a chi-square test confirms this claim. Specifically, the Chi Square test gave us a p-test value of 3.56E-10, which is well below the accepted confidence value of 0.05 (or 5.0E-2) so, that leads us to reject the hypothesis of independence, meaning that we found a strong indication that there is a relationship between the Function of the Reply Message and the health condition. For the Ovarian group, there is less information given (FM-02) and more Prayer (FM-08).

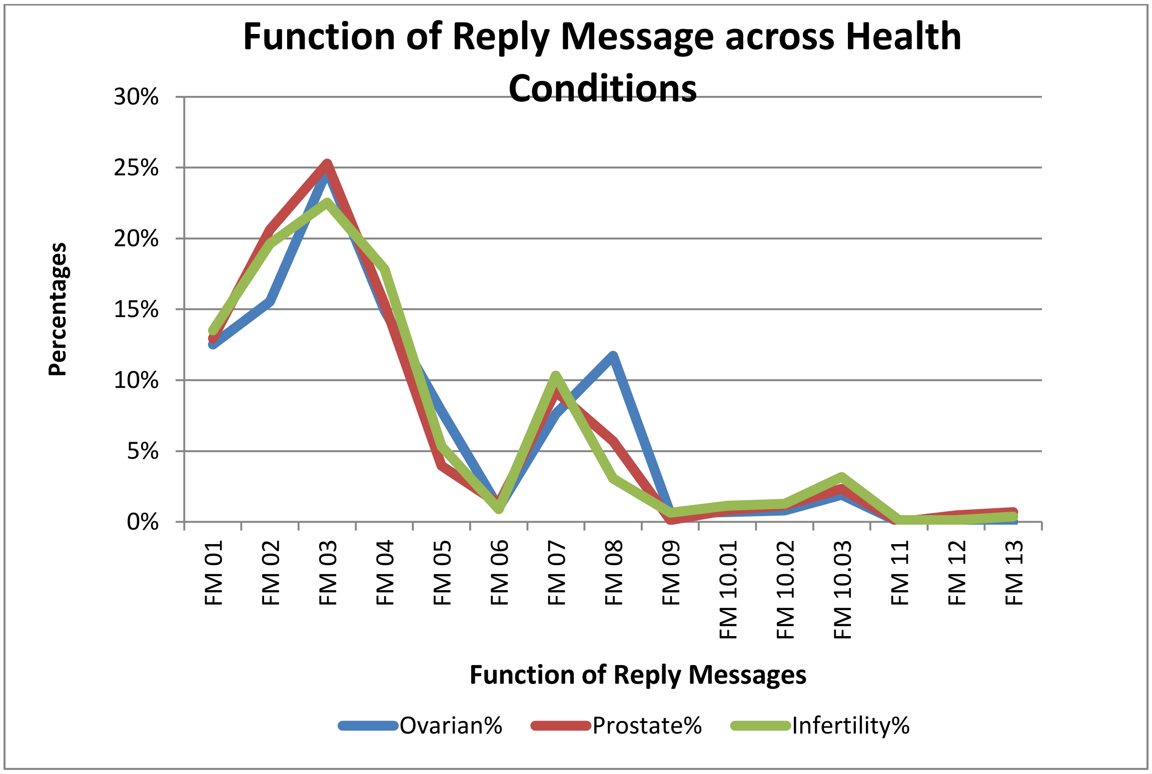

Figure 4.9 Distribution of Function of reply messages across health conditions

Overall, a small subset of the Functions of the Reply Message including: Describe_Experience, Info_giving, EncouragSupport & Info_seeking was found in the majority of posts which accounted for about 70% of the reply messages. Compared to the rest of the Functions of the Reply Message, the odds of finding reply messages belonging to this subset are about 2 times more likely for the Ovarian group, and about 3 times more likely for the Prostate and Infertility groups.

Cognitive Information Uses by Function of Reply Messages

Examining the relationships between information use categories and the Function of reply Messages, it was found that the subcategories that occurred together the most were IdentifyingPossibilities when the Function of Reply Messages were about EncouragSupport, acknowledging the usefulness of information (Ack_InfoUsefulness), and Thanks. The next pair with some co-occurrence instances was Ack_InfoUsefulness with NewImprovedUnderstanding (see Appendix C for a complete description).

Cognitive IUs subcategories
IU-01.01_NewImprovedUnderstanding
IU-01.02_IdentifyingPossibilities
IU-01.03_LearningManageStress
IU-01.04_LearningAvoidPitfalls
IU-01.05_HowInfoIsInterpreted
IU-01.06_GettingBetterInformed

Table 4.15 Distribution of Cognitive IUs by Function of Reply Messages

	Cognitive IUs						
Function of Reply Messages (FM)	**IU-01.01**	**IU-01.02**	**IU-01.03**	**IU-01.04**	**IU-01.05**	**IU-01.06**	**Totals**
FM-01_Info_Seeking	0	2	0	0	0	0	**2**
FM-02_Info_Giving	1	1	0	0	0	1	**3**
FM-03_ Describe_Experience	2	1	1	1	0	1	**6**
FM-04_ EncouragSupport	3	12	0	2	0	1	**18**
FM-05_ SocEmotional_Iss	2	0	0	0	0	1	**3**
FM-06_Humor	0	0	0	0	0	0	**0**
FM-07_Thanks	4	6	0	4	0	1	**15**
FM-08_Prayer	1	2	0	0	0	1	**4**
FM-09_ Ack_InfoUsefulness	0	1	0	0	0	0	**1**
FM-10.01_ Ack_CognitiveIU	7	10	1	4	0	1	**23**
Totals	**20**	**35**	**2**	**11**	**0**	**7**	**75**

A chi-square test could not be performed on this data because the tallies of several categories are below the minimum number of occurrences required. However, performing this test on only those categories with at least five occurrences, we find indications that the function of the message and the Cognitive information uses are independent (p-test=0.72).

Affective Information Uses by Function of Reply Messages

For the relationship between Affective IUs subcategories and the Function of Reply Messages, it seems that when the function of the reply messages were about Ack_AffectiveIU, Thanks, EncouragSupport, and

Describe_ Experience, the most frequently reported information uses were FeelingConnected2Others, IncrDecrFeelings, and StrengthenSelf-feelings.

Affective IUs subcategories
IU-02.01_StrengtheningSelf-feelings
IU-02.02_GettingMotivated2TakeAction
IU-02.03_BetterAble2Relax
IU-02.04_FeelingConnected2Others
IU-02.05_IncrDecrFeelings

Table 4.16 Distribution of Affective IUs by Function of Reply Messages

	Affective IUs					
Function of Reply Messages Codes (FM)	**IU-02.01**	**IU-02.02**	**IU-02.03**	**IU-02.04**	**IU-02.05**	**Totals**
FM-01_Info_Seeking	0	0	0	1	2	**3**
FM-02_Info_Giving	1	0	0	4	3	**8**
FM-03_Describe_Experience	3	0	0	8	5	**16**
FM-04_EncouragSupport	1	0	0	11	4	**16**
FM-05_SocEmotional_Iss	2	0	0	4	5	**11**
FM-06_Humor	2	0	0	0	0	**2**
FM-07_Thanks	7	0	1	10	9	**27**
FM-08_Prayer	3	0	0	3	0	**6**
FM-09_Ack_InfoUsefulness	0	0	0	3	2	**5**
FM-10.02_Ack_AffectiveIU	8	0	1	12	10	**31**
Totals	**27**	**0**	**2**	**56**	**40**	**125**

Due to the presence of several low-frequency categories, a chi-square test could not be applied to the data in the table. However, applying this test on the categories with the required minimum of five occurrences indicates that the Function of the Reply Message and the Affective information uses found are independent (p-test: 0.6).

Behavioral Information Uses by Function of Reply Messages

For the relationship between the Behavioral IUs category and the Function of Reply Messages, the most frequently reported information use was TakingActionBasedOnSuggest which also occurred when the function of the reply messages were Ack_BehavioralIU, Thanks, and Describing_Experience. Another frequently reported information use was TakingMoreActiveRole, which occurred when the Function of Reply Messages were Ack_BehavioralIU and Thanks.

Behavioral IUs subcategories
IU-03.01_Requested2ndOpinion
IU-03.02_TakingMoreActiveRole
IU-03.03_TakingActionBasedOnSuggest
IU-03.04_TalkingAboutCondition
IU-03.05_MakingChangesInLifeStyle

Table 4.17 Distribution of Behavioral IUs by Function of Reply Messages.

	Behavioral IUs					
Function of Reply Messages Codes (FM)	**IU-03.01**	**IU-03.02**	**IU-03.03**	**IU-03.04**	**IU-03.05**	**Totals**
FM-01_Info_Seeking	1	1	9	0	0	**11**
FM-02_Info_Giving	2	4	8	0	0	**14**
FM-03_Describe_Experience	2	6	20	0	0	**28**
FM-04_EncouragSupport	1	6	7	2	0	**16**
FM-05_SocEmotional_Iss	0	2	7	0	0	**9**
FM-06_Humor	0	0	3	0	0	**3**
FM-07_Thanks	3	12	34	4	2	**55**
FM-08_Prayer	0	2	6	0	0	**8**
FM-10.03_Ack_BehavioralIU	4	15	50	4	2	**75**
FM-11_Ack_NonInfoUse	0	1	3	0	0	**4**
Totals	**13**	**49**	**147**	**10**	**4**	**223**

A chi-square test could not be applied to the data in the table. Ignoring the low-frequency categories, we obtain a p-test of 0.86, which is greater than the confidence value of 0.05 and, therefore, we believe the Function of the Reply Messages and the Behavioral IUs category are independent.

Aggregated table for Information Uses by Function of Messages

The table below aggregates the information uses with respect to Function of the Reply Message into the columns Cognitive, Affective, and Behavioral from the Tables 4.15, 4.16 and 4.17.

Table 4.18 Distribution Function of the Message by Information Use

	Cognitive IUs n= 75		Affective IUs n= 125		Behavioral IUs n= 223	
Function Message Codes (FM)	**n**	**%**	**n**	**%**	**n**	**%**
FM-01_Info_seeking	2	3%	3	2%	11	5%
FM-02_Info_giving	3	4%	8	6%	14	6%
FM-03_Describe_Experience	6	8%	16	13%	28	13%
FM-04_EncouragSupport	18	24%	16	13%	16	7%
FM-05_SocEmotional_Iss	3	4%	11	9%	9	4%
FM-06_Humor	0	0%	2	2%	3	1%
FM-07_Thanks	15	20%	27	22%	55	25%
FM-08_Prayer	4	5%	6	5%	8	4%
FM-09_ Ack_InfoUsefulness	1	1%	5	4%	0	0%
FM-10.01_ Ack_ThinkingAbout	23	31%	0	0%	0	0%
FM-10.02_Ack_EmotionalReaction	0	0%	31	25%	0	0%
FM-10.03_Ack_DoingSomething	0	0%	0	0%	75	34%
FM-11_Ack_NonInfoUse	0	0%	0	0%	4	2%

A Chi Square test gives us a p-value of 3.5E-56, well below the threshold confidence level of 0.05 thus indicating the there is a significant relationship between the function of the reply message and the information uses.

Looking at the table for significant differences, at least 5%, we get that for reply messages encouraging support there are more references of cognitive information uses, and less behavioral information uses; for reply messages in which there is an acknowledgement that the poster is thinking about (FM-10.01) there more cognitive information uses; for reply messages acknowledging emotional reactions there are more affective information uses; and for reply messages acknowledging the poster is doing something there are more behavioral information uses.

2C: The Type of Questions Asked (QT):

Looking into the types of questions asked alone, it was found that from the extensive list of question types in QT (20 in all), all subcategories reported some frequency of occurrence but most of them were below 5%. Most participants' questions across the discussion groups chosen for this study were concentrated into three major subcategories: mainly Verification type questions, followed by concept completion type questions, and lastly, request type questions (see Appendix C for descriptions).

TABLE 4.19: Distribution of Question Types by OSGs

	Ovarian		**Prostate**		**Infertility**		**Totals**	
Question Type Codes	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**
QT-01_Assertion	4	2%	2	1%	3	1%	**9**	**2%**
QT-02_CausalAntec	2	1%	1	1%	2	1%	**5**	**1%**
QT-03_CausalConse	2	1%	1	1%	5	2%	**8**	**1%**
QT-04_Comparison	0	0%	0	0%	0	0%	**0**	**0%**
QT-05_ConceptCompletion	33	16%	37	21%	32	16%	**102**	**17%**
QT-06_Definition	6	3%	1	1%	5	2%	**12**	**2%**
QT-07_Directive	4	2%	2	1%	2	1%	**8**	**1%**
QT-08_Disjunctive	5	2%	8	4%	3	1%	**16**	**3%**
QT-09_Enablement	3	1%	3	2%	0	0%	**6**	**1%**
QT-10_Example	0	0%	0	0%	1	0%	**1**	**0%**
QT-11_Expectational	0	0%	2	1%	4	2%	**6**	**1%**
QT-12_FeatureSpecification	3	1%	0	0%	0	0%	**3**	**1%**
QT-13_GoalOrien	0	0%	0	0%	0	0%	**0**	**0%**
QT-14_Instrumental	1	0%	0	0%	0	0%	**1**	**0%**
QT-15_Interpretation	3	1%	12	7%	5	2%	**20**	**3%**
QT-16_Judgmental/Eval	6	3%	4	2%	8	4%	**18**	**3%**
QT-17_Procedural	5	2%	5	3%	1	0%	**11**	**2%**
QT-18_Quantification	7	3%	7	4%	14	7%	**28**	**5%**
QT-19_Request	30	14%	15	8%	13	6%	**58**	**10%**
QT-20_Verification	93	45%	80	44%	105	52%	**278**	**47%**
Totals	207		180		203		**590**	

Overall, it seems that participants across the three conditions were mainly interested in trying to verify concern, clarify doubts, get a confirmation, or elicit some guidance from peers as to how to proceed or act on the information they got. Participants were also interested in finding answers related to what-where-when-how states, events, or actions that could affect them.

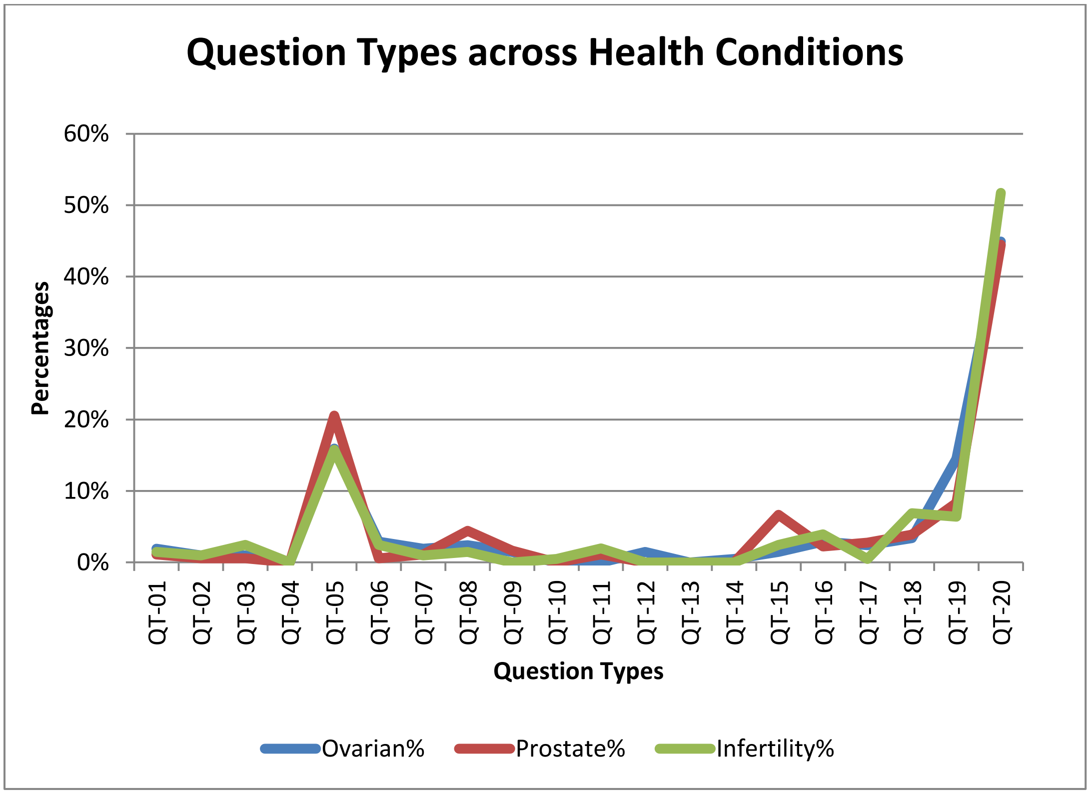

Figure 4. 10 Distribution of Question types across health conditions

The findings above are a good indication that types of questions asked are related to the support groups, and that the observations are not the result of random sampling. A chi-square test on the categories with the required minimum of occurrences gives us a p-test of 0.006, which is less than the well-accepted threshold of 0.05. Therefore, we can say with a very high degree of statistical confidence that question types are related to the health conditions considered. For the Prostate group, we have more Concept Completion (QT-05) and Interpretation (QT-15) type of question. Within the

Ovarian group, we have more Request questions (QT-19) and within the Infertility group we have more Verification questions (QT-20).

Overall, a small subset of question types that allow people to directly inquire about specific aspects of the immediacy of their health condition dominated all the others. This subset which included: verification, concept completion, request, or quantification questions accounted for about 73% of all questions types. Compared to the rest of the question types, the odds that a post would contain a question from the predominant subset are about three times more likely across all three conditions.

Cognitive Information Uses by Question Type:

Examining the relationships between these categories found few co-occurrences among them. Mainly, the information use category, IdentifyingPossibilities, occurred when the question types were Verification and Request, followed by NewImprovedUnderstanding which happened when Request question types were asked.

Cognitive IUs subcategories
IU-01.01_NewImprovedUnderstanding
IU-01.02_IdentifyingPossibilities
IU-01.03_LearningManageStress
IU-01.04_LearningAvoidPitfalls
IU-01.05_HowInfoIsInterpreted
IU-01.06_GettingBetterInformed

Table 4.20 Distribution of Cognitive IUs by Question Types

	Cognitive IUs						
Question Type Codes (QT)	**IU-01.01**	**IU-01.02**	**IU-01.03**	**IU-01.04**	**IU-01.05**	**IU-01.06**	**Totals**
QT-01_Assertion	0	1	0	0	0	0	**1**
QT-05_ConceptCompletion	1	0	0	0	0	0	**1**
QT-07_Directive	0	1	0	0	0	0	**1**
QT-08_Disjunctive	0	0	0	1	0	0	**1**
QT-16_Judgmental/Eval	1	0	1	1	0	0	**3**
QT-17_Procedural	1	0	0	0	0	0	**1**
QT-19_Request	3	4	0	0	0	0	**7**
QT-20_Verification	1	5	0	2	0	1	**9**
Totals	**7**	**11**	**1**	**4**	**0**	**1**	**24**

A chi-square test could not be applied on the data in the table above. Even after ignoring the low-frequency categories, there were not enough categories to perform the test.

Affective Information Uses by Question Type:

Examining the relationships between these categories, the primary occurrences of Affective IUs categories with particular question types were that of IncrDecrFeelings when Verification, Request, and Assertion question types were asked, followed by that of FeelingConnected2Others when Assertion, Verification, and Request question types were asked.

Affective IUs subcategories
IU-02.01_StrengtheningSelf-feelings
IU-02.02_GettingMotivated2TakeAction
IU-02.03_BetterAble2Relax
IU-02.04_FeelingConnected20thers
IU-02.05_IncrDecrFeelings

Table 4.21 Distribution of Affective IUs by Question Types

	Affective IUs					
Question Type Codes (QT)	**IU-02.01**	**IU-02.02**	**IU-02.03**	**IU-02.04**	**IU-02.05**	**Totals**
QT-01_Assertion	0	0	1	5	3	**9**
QT-05_ConceptCompletion	1	0	0	0	0	**1**
QT-07_Directive	1	0	0	0	0	**1**
QT-09_Enablement	0	0	0	0	1	**1**
QT-11_Expectational	3	0	0	0	0	**3**
QT-15_Interpretation	0	0	0	0	1	**1**
QT-16_Judgmental/Eval	1	0	0	1	1	**3**
QT-17_Procedural	0	0	0	0	1	**1**
QT-19_Request	4	0	0	3	3	**10**
QT-20_Verification	6	0	0	4	4	**14**
Totals	**16**	**0**	**1**	**13**	**14**	**44**

A chi-square test could not be applied on the data in the table above. Even after ignoring the low-frequency categories, there were not enough categories to perform the test. The only way to determine if there is any relationship among these variables is by aggregating the subcategories of affective IUs into one.

Behavioral Information Uses by Question Types:

Examining the relationships between these categories, most co-occurrences of Behavioral IUs subcategories with particular question types were that of TakingActionBasedOnSuggest with Verification type questions, followed by ConceptCompletion and Request question types. Also showing some co-occurrence was TakingMoreActiveRole with Verification type questions.

Behavioral IUs subcategories
IU-03.01_Requested2ndOpinion
IU-03.02_TakingMoreActiveRole
IU-03.03_TakingActionBasedOnSuggest
IU-03.04_TalkingAboutCondition
IU-03.05_MakingChangesInLifeStyle

Table 4.22 Distribution of Behavioral IUs by Question Types

	Behavioral IUs					
Question Type Codes (QT)	**IU-03.01**	**IU-03.02**	**IU-03.03**	**IU-03.04**	**IU-03.05**	**Totals**
QT-01_Assertion	0	1	2	0	0	**3**
QT-02_CausalAntec	0	0	1	0	0	**1**
QT-03_CausalConse	1	0	2	0	0	**3**
QT-05_ConceptCompletion	0	1	6	1	1	**9**
QT-07_Directive	0	0	2	0	0	**2**
QT-08_Disjunctive	0	0	1	0	0	**1**
QT-09_Enablement	0	1	0	0	0	**1**
QT-12_FeatureSpecification	0	0	1	0	0	**1**
QT-14_Instrumental	0	0	2	0	0	**2**
QT-16_Judgmental/Eval	0	1	4	0	0	**5**
QT-17_Procedural	0	1	1	0	0	**2**
QT-18_Quantification	0	0	2	0	0	**2**
QT-19_Request	1	1	6	0	0	**8**
QT-20_Verification	4	11	24	4	1	**44**
Totals	**6**	**17**	**54**	**5**	**2**	**84**

A chi-square test could not be applied to the data above. However, if we ignore the low-frequency categories, a chi-square test gives us a p-test of 0.86, which is an indication that the Question Type and the Behavioral IUs category of are independent.

Aggregated table for Information Uses by Question Types

The table below aggregates the information uses with respect to Question Types into the columns Cognitive, Affective, and Behavioral from Tables 4.20, 4.21, and 4.22.

Table 4.23 Distribution Question Type by Information Use

	Cognitive IUs n= 24		**Affective IUs n= 44**		**Behavioral IUs n= 84**	
Question Type Codes (CT)	**n**	**%**	**n**	**%**	**N**	**%**
QT-01_Assertion	1	4%	9	20%	3	4%
QT-05_ConceptCompletion	1	4%	1	2%	9	11%
QT-16_Judgmental/Eval	3	13%	3	7%	5	6%
QT-19_Request	7	29%	10	23%	8	10%
QT-20_Verification	9	38%	14	32%	44	52%

A Chi Square test yields a p-value of 0.028. This indicates, with a high degree of confidence, that there is a significant relationship between the question types and the information uses. Looking at the table for significant differences (at least 5%), we get that posts containing assertion questions have more incidences of affective information uses; for messages containing concept completion questions there are more behavioral information uses; for postings containing judgment or evaluation questions there are more cognitive information uses; for messages containing request questions there are less behavioral and more cognitive information uses; and for postings containing verification questions there are more behavioral and less affective information uses.

4.4. SUMMARY OF FINDINGS

- There is a significant relationship between who has condition issues and gender. In particular interest, within the infertility group we found that whether the participant indicates that itself or a relative has condition issues or doesn't indicate it at all, the gender identified is overwhelmingly female.

- There is a significant relationship between Content types and Information Uses when the IUs subcategories were aggregated (Table 4.13). For diagnostic testing there are less incidences of cognitive information uses; for treatment there is less affective and more cognitive information uses; and for posting containing non-medical remarks there are more incidences of affective information uses, and less of cognitive information uses.

- There is a significant relationship between Function of reply messages and Information Uses when the IUs subcategories were aggregated (Table 4.18). For reply messages encouraging support there are more references of cognitive information uses, and less behavioral information uses. Approximately 60% of the function of the reply messages had to do with providing information, describing a personal experience, asking for information, and providing encouragement and support to better address the original post (Table 4.13).

- There is a significant relationship between Question types and Information Uses when IUs subcategories were aggregated (Table 4.22). Assertion questions have more incidences of affective information uses; Concept completion questions show more behavioral information uses; Judgment or evaluation questions show more cognitive information uses; request questions show less behavioral and more cognitive information uses; and for verification questions there are more behavioral and less affective information uses. Almost 50% of all the question types found in the posted messages were verification questions. Together with making requests and concept completion questions, these question types form 75% of all question types found (Table 4.17).

- There is a significant relationship between the content type and the type of condition. For the prostate group, there is less symptoms (CT-01) and less medication (CT-06); more diagnostic testing (CT-07) and treatment (CT-10). Regarding messages' content, about 60% of posts dealt with diagnostic testing, medications and treatment, followed by a 12% of instances related to symptoms and prognosis (Table 4.9).

- We found a significant indication that there is a relationship between the Function of the Reply Message and the type of condition. For the ovarian group, there is less information given (FM-02) and more prayer (FM-08).

- We can say with a very high degree of statistical confidence that question types are related to the type of conditions considered. For the prostate group, we have more concept completion (QT-05) and interpretation (QT-15) type of question. Within the ovarian group, we have more request questions (QT-19) and within the infertility group we have more verification questions (QT-20).

- We did not find a statistically significant relationship between the information use categories (cognitive, affective and behavioral) and the ovarian, prostate, and infertility support groups (Tables 4.6, 4.7, 4.8).

- No significant relationship was found between the cognitive, affective or behavioral information uses and the types of conditions.

CHAPTER SUMMARY

The first research question asked about what types of information use behaviors are disclosed in online support groups according to participants' characteristics. A content analysis of each thread of conversation across all three support groups of the study indicated more female than male participation in the OSGs and that men's participation was low even in the gender-neutral condition.

Data also showed participants seemed more inclined to share Behavioral Information Uses than to share Cognitive or Affective behaviors. Among those Behavioral Information uses,*"TakingActionBasedOnSuggestion"* was substantially the most frequently reported IU, followed by *"TakingMore ActiveRole"* & *"TalkingAboutCondition"*. In the case of the Affective behaviors, FeelingConnected2Others was the most amply reported behavior, followed by *"IncrDecrFeelings"* and *"StrengtheningSelf-Feelings".*

The Cognitive category had the least instances of reported Information Uses among all the three categories and within it, *"IdentifyingPossibilities"* reported the highest scores followed by *"NewImprovedUnderstanding"* & *"LearningAvoidPitfalls".*

The second research question asked about how message characteristics (content type, question type and function of message) relate to the information use behaviors disclosed by participants.

Results of the content analysis indicate that there is a dependent relationship present between the message characteristics of content type, question type, and the function of messages with the types of conditions. Similarly, research also shows that when each of the subcategories within the cognitive, affective and behavioral categories are aggregated then the data show there is a significant relationship among the variables.

The analysis also suggested that for information use to occur there must be some interactive feedback to the questions being asked. For an interactive feedback to occur, full interaction should be present, which means that there must be two or more participants, and that messages need to relate to previous ones with a response to the question being asked. The data also showed a low rate of responses contributed to difficulty in evaluating the independence of the variables.

CHAPTER 5: DISCUSSION AND IMPLICATIONS

5.1. INTRODUCTION

The purpose of the research was to gain a better understanding of online health information use by looking into interactions in threads of consumer health discussion groups of three chronic conditions with the expectation of contributing to the overall understanding of the role that health information use behaviors can play in the satisfaction of health consumers' needs. Also, a more appropriate understanding of these behaviors could be useful in the design of better online information e-health[27] services.

This research addressed the following general research questions:

- What is the role that peer-to-peer interaction plays in helping health consumers satisfy their information needs and engage in information use behaviors that affects their health outcomes?

- What are the factors related to the effects of using information that might lead consumers to carry out different health behavior outcomes?

The more specific research questions are shown below:

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[27] "e-health is an emerging field at the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies." (Eysenbach, 2001)

RQ1: What types of information use behaviors are disclosed in online support groups according to participants' characteristics?

1a: What specific cognitive information use behaviors were disclosed?
1b: What specific affective information use behaviors were disclosed?
1c: What specific behavioral information use actions were disclosed?

RQ2: How do message characteristics relate to the information use behaviors disclosed by participants?

2a: In terms of the health-related message content (CT)?
2b: In terms of the types of questions asked (QT)?
2c: In terms of the functions of the reply messages (FM)?

Both research questions were tackled using content analysis methodology. The sample data was comprised of 150 threads of online conversations containing a total of 1,097 individual posts. These threads were collected following the selection rules as discussed in Section 3.7.2. For this study, the data that was analyzed consisted of each posted message within each of the sampling units (threads).

This chapter provides a discussion of the limitations and benefits of the study findings, draws conclusions from the results, and also discusses the study implications related to information use behavior in general. Areas of future research are outlined as well.

5.2. DISCUSSION OF FINDINGS

As part of the characterization of the data, and compared with results from other researchers, this study found that more women than men, 67% vs. 26%, respectively, participated in online health discussion groups (as shown in Section 4.2), which is consistent with what several earlier studies had indicated—that more women search for online health-related information (Ybarra & Suman, 2006; Andreassen et al., 2007; Hallyburton & Evans, 2014). Macias et al.'s, (2005) study found that 71% of women in contrast to 51% of men used online health information. In contrast, Fox and Fallows's (2003) reported closer participation ratios between women and men (85% vs. 75%, respectively).

Other previous research by Nupur's (2010) and Ginossar's (2011) had shown that not only were participation rates of females for health-related purposes higher, but their participation also occurred more frequently than males. Similarly, a few researchers (Klemm et al., 1999; 2006; Blank & Adams-Blodnieks, 2007; Gooden & Winefield, 2007) reported that men and women have different online behaviors, and more specifically, that men are more interested in retrieving and sharing information and facts compared to women, who are more interested in securing and providing emotional support. This study, then, made the assumption that there would be differences in participation by people with different gender-based conditions and their respective information uses.

About Gender participation

In terms of male vs. female participation in the selected groups, this research data (see Tables 4.2, 4.3, and 4.4 in Section 4.2 for details) shows that male participation in the female-oriented discussion groups was minimal to almost nonexistent (about 3% or less) whereas females' participation in the male group was almost four times as much (about 11%); this finding is similar to that of Katz's (2012), whose study reported that "female relatives or friends of men with prostate cancer post messages on the prostate support group more frequently and in greater detail than the men with prostate cancer themselves" (p. 155).

About who has condition issues?

In regard to whom the searched information was intended for, the data shows that the vast majority of participants (73%) reported that they themselves had the condition issues, a finding supported by previous research (Atkinson, Saperstein, & Pleis, 2009; Powell, Inglis, Ronnie, & Large, 2011). This finding, however, is in contrast to Fox and Duggan's (2013) research; they found that about 39% of those who conducted health searches did so for themselves and 39% searched on behalf of someone else. The discrepancy between the results of this research and Fox and Duggan's (2013) could be based on the fact that people now know more about and feel more comfortable participating in OSGs by themselves than they did just a few years ago. Another possible explanation of these differences could be related to the type of conditions reviewed. Participation rates for other conditions might differ from those researched in this study, and this would need to be researched further.

About Information Use instances

In terms of the number of reported information use instances (see Table 5.1 below), the non–life-threatening condition (infertility) showed slightly higher frequencies across all the three types of information uses (cognitive, affective, and behavioral). Within the life-threatening conditions (ovarian and prostate cancer), the reported frequencies varied only by two to five incidences across each of the three types of IUs.

Table. 5.1 Number of Reported Cognitive, Affective, and Behavioral IUs per Condition. Chi-square p-test of 0.950873.

Chronic Conditions	**Number of Reported Cognitive IUs**	**Number of Reported Affective IUs**	**Number of Reported Behavioral IUs**	**Totals**
Chronic Life-Threatening Condition **(Ovarian)**	6	9	24	39
Chronic Life-Threatening Condition **(Prostate)**	8	10	21	39
Chronic Non–Life-Threatening Condition **(Infertility)**	10	15	30	55

Participants in the online health support groups studied reported more occurrences of behavioral actions being taken than effects on their affective behavior or their cognitive behaviors. In wondering why they reported more behavioral actions, it may be that people might find it easier to recall and report on concrete things they have done than to express how they felt or what they thought at a given moment after interacting with information exchanged in the OSGs. In terms of what specific behaviors were reported, “taking action based on suggestions” had the highest score within the Behavioral IUs category followed by “taking a more active role.” Within the Affective IUs category, the most reported feelings were “feeling connected to others” followed by “increased or decreased feelings.” And within the Cognitive IUs category, “identifying possibilities” was the most reported behavior followed by “gaining new understanding.”

In reality, it turned out that this data did not show many significant differences between health information uses by the different gendered conditions which seems to concur with Mo’s et al., (2009) and Owens’ et al., (2010) research where no major gender differences were found in the use of OSGs. Part of the reason could be that men are not as much interested in OSGs participation, as supported by O'Brien, Hunt and Hart's (2005) claim that “men health behavior tends to be: consult late, consult less and often relying on their female partners to worry about their health” (p. 2). Another possible reason could be the fact that even within support groups for men conditions, such as prostate cancer, there seems to be more female participants that men themselves (Seale, 2006; Katz, 2012) which would make the study sample more homogenous. It has also been reported that online interaction may in fact ”mitigate the gender differences previously observed in face-to-face communities” (Mo et al., 2009, p. 17) making them less evident but results are still inconclusive. It could also be that the demographics tendencies of online information behavior might be changing.

About Function of Messages

Regarding information provision, the results of this study (about 24% of the posts were about describing experiences, and 18% were about information giving) seem to show that participants are more willing to share personal health information when they think it could help others; this parallels Savolainen's (2011) research, where about 42% provided response information drawn heavily on personal knowledge.

A chi-square analysis of Table 5.1 above, showed a high degree of confidence, a p-test of 0.95, which indicates that the type of health condition is independent of the information use behaviors; that is, there is no significant relationship.

Findings about whether the discussions focused more on information exchange or social support are mixed. For example, in Ginossar's (2011) study, the discussion centered on information exchange, and the emotional aspects of coping were communicated in addition, not as the main focus. In contrast, Chen's (2012) analysis of the conversation content from support groups of poorly understood or socially stigmatized chronic conditions, such as breast cancer, diabetes, and fibromyalgia, found that their most common usage pattern centered around support. Results of the study reported here agree with Chen's (2012) as the Describe Experience subcategory is expressed in terms of the support-centered subcategories (Encouragement & Support, Socio Emotional Issues, Humor, Thanks, Prayer). On the other hand, when the Describe Experience subcategory is portrayed more toward the information centered subcategories (Info Seeking, Info Giving, Acknowledge Info Usefulness, Technical Board Issues) then this research agrees with that of Ginossar's (2011).

5.3. IMPLICATIONS OF THE RESEARCH

The findings reviewed in the previous section will be discussed here in terms of their implications.

5.3.1. IMPLICATIONS FOR THE MODEL

The results of this study in terms of the Model of Ecological Constructionism imply that Social Systems (group practices from people’s daily setting, including communication exchanges from discussion groups) related to online health support groups do seem to follow the model. In fact, we found that variables in the social system of this study (Content type, Function of Reply Message and the Question type) do have a significant relationship with the threefold cognitive, affective and behavioral Information Uses emerged during participants' interaction with online health discussion groups related to chronic conditions.

It is important to notice that the study only shed light on the associations between these variables but it does not actually show a causal relationship.

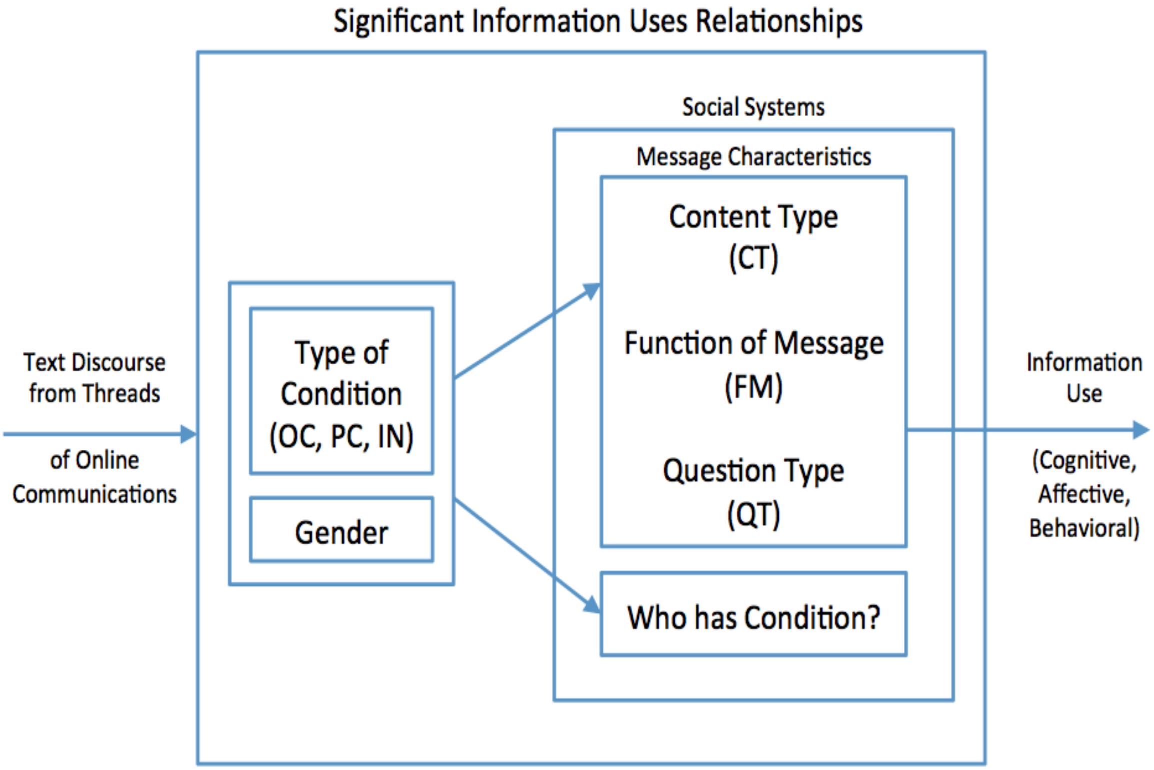


Figure 5.1 Significant Information Uses Relationships

5.3.2. THEORETICAL IMPLICATIONS

This research breaks new ground in the way that it brings together different bodies of literature, consumer health information, information use behaviors, and online discussion groups for a deeper understanding of how consumers interact with online discussion groups and the impact of those forums. Research findings enable health providers to develop a clearer understanding of consumers' health information use behaviors, so that more adequate health interventions can be developed and tested, potentially increasing consumers' compliance and quality of life.

This work could also serve as a starting point for future research to examine what minimal level of interaction should be observed before IHC can have a measurable impact on behavior.

Findings could allow the designers and developers of health-related online sites to create better user-friendly tools and facilitate participants' reporting of the uses given to information shared on the discussion board. For example, developers can create built-in features that can categorize, sort, or rank postings based on content, to make actions easier to identify and track. These kinds of design features are being used for shoppers, but are not clearly or purposefully being used for health consumers in online forums.

Understanding how OSGs impact patient behavior could make them a valuable tool in future efforts to manage chronic diseases, which are the leading cause of morbidity, disability, and mortality in developed countries, and a driver of present and future health care costs. Regarding specific findings of the current research, some data and reflection with implications for future research are noted below:

The data shows that there was more information uses reported in the infertility (IN) group than in the ovarian and prostate groups. One possible rationale is because in the IN group there are a larger number of standard and alternative treatments which are also low risk. Hence, the low-risk nature of those treatments as well as the fact that IN is a non–life-threatening condition give participants more confidence to try and report on different things. The research data also shows that there were more behavioral uses disclosed than cognitive or affective uses, and one likely explanation is that an action taken can be replicated by others and can leave a trace or record, which makes it easier to remember than, say, a feeling or a thought. So, behavioral actions are easier to identify and easier for people to report. Even so, the data clearly shows that participants act upon the information they encounter or receive in the context of illness discussion forums.

Another highlight of the data was that the NonMedical_Remarks subcategory of message content had more reported information uses than the other subcategories. In this case, the researcher believes that the lack of SG moderator and censoring tools allows people to post about other topics freely. Also, when people “connect” they may be more willing to talk about other things related to daily living or how they feel affected by issues related to the condition, which is what many NonMedical_Remarks instances were about. For some of those NonMedical_Remarks, it would likely be important to have separate subcategories for: (1) the feelings, worries, and concerns experienced as a result of dealing with the specific medical condition (emotional state); (2) the perceived need to find the right doctor or right medical facility; and (3) discussion of insurance coverage and costs associated with dealing with the condition. Some of the other remarks that would appropriately fit into the NonMedical_Remarks subcategory include: clarifications, general suggestions, giving thanks for the feedback, cheering up others, and giving details of daily life personal issues. The prominence of nonmedical remarks also illustrates the holistic and organic nature of illness, which encompasses medical and nonmedical elements of experience.

When trying to understand why participants more often reported feeling connected to others when the reply messages they got were about encouragement or support, it seems that in many cases, people go to these forums to find others going through the same thing. When they find other people with the same health condition online, there is a feeling of belonging, of “being on the same boat,” that people find highly comforting and reassuring, and they seek more of it. Communicating with others (along with helping or encouraging others) in the same situation initiates a feedback loop of empowerment, gratitude, and support. Also, some research suggests (Grimes et al., 2010) that people tend to express positive sentiments more often in systems such as online support groups that are based on reflections of personal experiences. More specifically:

> For replies encouraging support there are more references of cognitive information uses, and less behavioral information uses. For reply messages where there is a cognitive, affective or behavioral acknowledgement, then there are more cognitive, affective and behavioral information uses respectively.

The types of questions that were most frequently asked across all conditions were verification type questions. It seems reasonable that when people go to online SGs, they not only want support, or more information, or suggestions for alternative treatments, but they also want to make sure that what they are thinking, feeling, or want to do is ok or had worked for others in a situation similar to theirs. They look for a basis, means, or reason to empower themselves. They want confirmation or verification from others who have “been in their shoes” and who they perceive to give more appropriate suggestions than others who are not or have not been in the same or similar situation. More specifically:

> Posts containing assertion questions have more incidences of affective information uses; for postings containing judgment or evaluation questions there are more cognitive information uses; for messages containing request questions there are less behavioral and more cognitive information uses; for messages containing concept for postings containing verification questions there are more behavioral and less affective information uses.

When looking for the implications of types of conditions and the medical Content types, it was found that for the prostate group, there is less symptoms (CT-01) and less Medication (CT-06); more Diagnostic Testing (CT-07) and Treatment (CT-10).

In the case of the type of conditions and the function of message within the Ovarian group, the implication seems to be that we have less information given (FM-02) and more Prayer (FM-08)

For the implications between type of condition and Function of messages, it was found that for the Prostate group, we have more Concept Completion (QT-05) and Interpretation (QT-15) type question. Within the Ovarian group, we have more Request questions (QT-19). And within the Infertility group, we have more Verification questions (QT-20).

Lastly, looking into the implications between content type and information uses, it was found that for postings containing non-medical remarks there are more incidences of affective information uses and less cognitive information uses; for Diagnostic testing there are less incidences of cognitive information uses; and for Treatment there is less affective and more cognitive information uses.

5.3.3. PRACTICAL IMPLICATIONS

Even though, as pointed out by Savolainen's (2001), it is believed that one of the strengths of the Internet is the interactivity between participants, when looking into the interactions within the discussion groups, it became evident that, for the most part, participants (information seekers) did not explicitly give feedback for every response received or about how they used the information they received, even though each feedback response could have been very useful to others. More often, they just tended to show gratitude for the feedback but provided no further explanations or indications. Some reasons why participants' may display lack of sharing are because they don't reflect on the value of the information or support they provide, or simply because that they just neglected to provide the extra information as Grimes et al.'s (2010) analysis of clips suggests.

This lack of reflection-based sharing was definitely observed in this investigation and suggests that future research should consider analyzing more data by surveying participants similar to Amazon.com who asks buyers to respond to “Was this information useful?” in order to get participants to self-reflect and report their health information uses more consistently and more often.

As reported in Hong et al.’s (2012) study, even though research about online support groups had gained considerable momentum over the last two decades, outcome-related research (which assesses the effects of Internet health information use) is still limited and deserves special attention, as it can be used to provide evidence to further develop Internet-based interventions and online resources to support the growing number of health consumers.

The researcher anticipates that even if one of the newer social media technologies were used instead of the OSGs, the types of uses found here would likely be very similar because they’re based on how the participants were able to be helped by peer-to-peer sharing of information and support. The type of media used can make a difference in terms of how much information is disclosed and in terms of the level of privacy each provides.

While the individual reports are anecdotal, subjective, and may not be statistically representative of the whole patient population, this pattern of seeking and providing information is a representative dynamic of emergent online patient communities and consistent with other researchers' findings. While further research will be helpful, the findings point to some significant current trends that are established and growing.

Some of the findings in this study were supported by those of Hu et al.'s (2012) study of information seeking prior to medical appointments; they reported some similar information uses (such as participants intending to use information to ask questions of doctors based on information received, asking for a second opinion, requesting tests or procedures). The difference between their research and this study was that they reported only on patients' intended use of information before a medical appointment, as opposed to how the information received affected participants cognitively, affectively, or behaviorally.

One implication of this research is that by understanding how health consumers use information from online discussion groups, health providers, health educators, and media designers can learn how to "tailor the content and presentation of their platform in a way that it can add usability and increased motivation to disclose information online when needed" (Bansal, Zahedi, & Gefen, 2010). Health practitioners would also be able to guide their patients into making more appropriate choices and avoiding possible risks. They could encourage or create opportunities for patient participation in OSGs, which would foster a more proactive engagement in managing their disease, especially for those with a chronic condition.

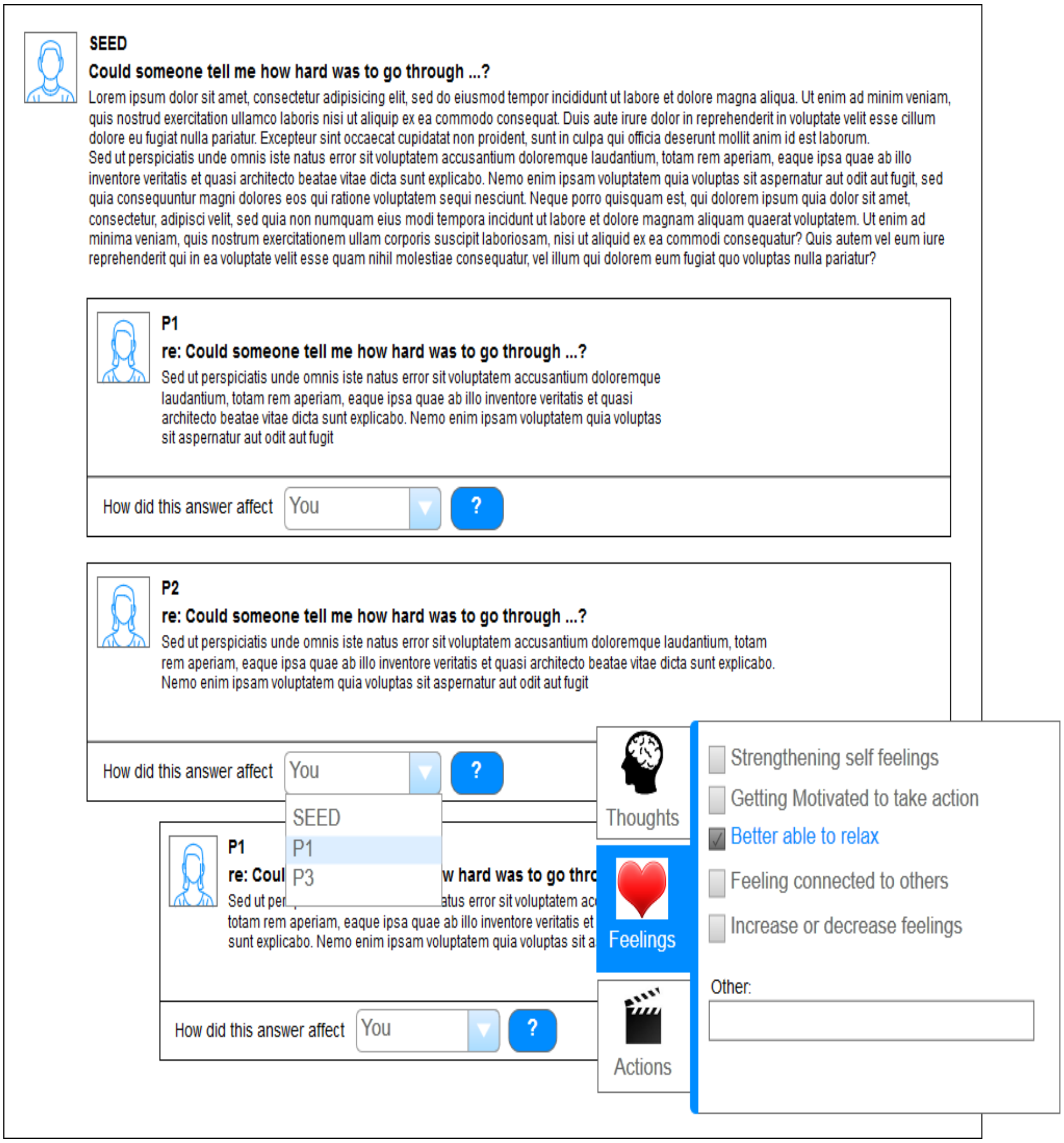
For participants of online support groups, having a better understanding of how others have used information exchanged would give them more confidence into relating to others, and would help them to visualize alternatives to treatments received from fellow participants that have experienced “what it might be like” to have a particular healthcare process or outcomes (Entwistle et al., 2011).

Research on consumers’ uses of online tools like the discussion groups analyzed in this study is still in its early stages. Even though this research does not focus on why people use health information, is important to mention Wagner and Hibbard's (2001) research where they found that the increased use of health information was due to the “free information effect rather than to an advertising effect” (p. 595) because it raises the expectations that people would also be using more information from health discussion boards due to its free accessibility.

While awareness of the online information use phenomenon is growing rapidly, it remains a challenge to capture the complex nature of online behavior, interaction, and, especially, outcomes. Approaches such as this model can be incorporated into future projects to expand awareness and use of online interactions and resources, as the need for reliable and responsible online resources continues to increase. With current trends such as metaliteracy, patient empowerment, and telemedicine, the need for reliable and responsible use of online health resources is growing.

Some current studies related to the use of online health information for health promotion (Webb, Joseph, Yarley, & Michie, 2010; Lee et al., 2014a) indicate that social media can successfully encourage health improvement and behavior change as long as consumers can be able to understand and utilize relevant information.

One way of increasing health consumers' chances of being successful at behavioral change would be a better understanding of how they are affected while making use of the information they receive online, as in the case of the online support groups studied here. Thus, newer discussion boards or online forums could use these research findings as a tool to gathering data on what kinds cognitive, affective, and behavioral information use effects are being experienced by their participants as well as which ones seem to have a higher impact on their well-being when dealing with all the issues that surround their conditions. For example, if these boards are created by a medical practice for their patients, then the doctors and other health practitioners could use the data gathered to better customize the health interventions they prescribe to each of the patients and so increase the likelihood of effective behavior change, especially for people with chronic conditions. See Figure 5.2 below, which is a mock-up prototype image of what a newer online health support board could look like.



SEED

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How did this answer affect: You

P2

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How did this answer affect: You

P1

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How did this answer affect: You

☐ Strengthening self feelings
☐ Getting Motivated to take action
☑ Better able to relax
☐ Feeling connected to others
☐ Increase or decrease feelings

Other:

Figure 5.2 Mock-up Prototype of a Newer Online Health Support Board

Results from this study may make evident that more research is needed to show whether information use behaviors are independent from other contexts. And even more research is needed to determine whether the communication medium (online SGs in this research) or other factors have any effects on the information use behavior exhibited by the participants.

5.4. DISCUSSION

This work set out the goal to identify and separate the significance and relative weight of key response variables (outcomes) from a patient perspective, by developing a new model of health forum interaction that is based upon rigorous content analysis of health forum posts. Through this modeling, the current dissertation captures and quantifies key aspects of meaning-making, while showing that online health forums matter for outcomes, having the potential to shape the participants' behaviors in multiple, practical, useful ways.

Overall, the data shows that there were several significant relationships among the variables studied here. Content type, Function of Reply Messages, as well as Question type all show a dependent relationship with the types of conditions (OC, PC, and IN) likely suggesting that: the type of health conditions do have an influence in the types of medical content that matters to participants and hence are more frequently discussed; or that the type of condition affect the type of function of reply responses that are more likely to be sent such as those dealing with information provision or description of personal experiences; or that the type of conditions determine the types of questions more likely to be asked.

Results from the data analysis also show that when the information uses categories are aggregated (no specific subcategories) then there is a significant relationship between Content type, Function of Reply Messages, and Question type with Information uses. This seems to suggest that messages characteristics do have some influence in the type of information uses revealed by participants in online health support groups. Likely, when discussing serious issues such as medical treatment then participants will presumably express more cognitive information uses than affective ones; or than when participants get encouraging messages cognitive information uses are more probable to be reported; or that when participants ask verification questions to others, then they express taking more behavioral actions than expressing feeling. People seem to rather follow the advice of strangers than to trying to get a second opinion from professionals. This may be the result of people following "this worked for me" kind of advice, possibly under the impression that such actions would carry little negative consequences and that may be worth "give them a try." The data seem to suggest that most replies are made with the intention of being helpful, in a variety of ways.

This research finding that describing experiences was the most frequently reported message function is supported by some researchers beliefs that individuals are more willing to share personal healthcare information when they think it could help others (Hummel, 2016) and they suggest that awareness that one's online interactions have a measurable impact upon others' behaviors can be encouraged and enhanced purposefully in different contexts, for example, for the management of chronic disease (George, Rovniak, & Kraschnewski, 2013). Their research also shows how the benefits a community get from the use of health information resources tends to increase with greater public participation in certain information-sharing activities, akin to the effects of social behavior reported in crowdsourcing communities.

Data also shows significant that gender and who has condition issues also have a significant relationship within the specific online support groups of the study. What this seems to mean is that even within gender-neutral online health support groups such as infertility, female participation is the overwhelming majority. Women seem to post more and more often for themselves and for others.

Like oral illness narratives in other places, online health support postings are rich in both content and context information regarding the social and behavioral aspects of health, illness, and treatment. Health consumers share experiences in order to feel better, explore options, increase knowledge, or reduce anxiety about choices and uncertainties in the course of illness and treatment. In the process, they gain understanding regarding alternatives or develop new interpretations about their situation. Participants report that they do indeed feel relief after participating in information-sharing activities; online forum data patterns indicate that health forum information exchange can have a measurable and real impact on consumers' behaviors, although feedback is not always given.

Patient self-management is an essential ingredient in the future selfcare of all chronic diseases, with a diversity of online discussion forums providing needed information and support at a distance. By collecting and organizing information use data in rigorous and purposeful ways, as demonstrated in this research study, new communication technologies and evolving information use habits could assist current efforts to control healthcare costs and manage chronic disease.

5.5. ASSESSING THE QUALITY OF THE STUDY

In order to assess the quality of the study and its findings, it was important to the researcher to take measures that would ensure its trustworthiness. Criteria used in traditional research look at trustworthiness in terms of its validity (internal and external), reliability, and objectivity, which are parallel terms to those proposed by Lincoln and Guba's (1985), namely: credibility, dependability, confirmability, and transferability.

5.5.1. CREDIBILITY

The idea behind credibility is to assess how believable the data collected from the participants is as well as whether the researcher was able to represent participants' intended meanings. Since the data was collected from past postings of the selected OSGs, participants' meanings regarding their information uses were taken as stated, and so there was no possibility of introducing a Hawthorne effect[28]. Among the criteria used to access the 'goodness of a research'[29], a number of strategies were useful: collection of data over an extended period of time, collecting data from different online resources, and triangulating by means of doing both qualitative and quantitative analysis of multiple-case groups, which as stated, helps strengthen the validity and stability of the findings.

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[28] "Hawthorne effect is defined as a tendency for subjects of research to change their behavior simply because they are being studied." (Vogt, 1999)

[29] Goodness of research: refers to the perspectives and principles that guide the evaluation of the quality of qualitative research. (Fossey, Harvey, McDermott, & Davidson, 2002).

5.5.2. TRANSFERABILITY

Transferability refers to the extent to which the results of a study can be applicable to other contexts. This study investigated information use in online health discussion groups so it is important to notice that results are not extrapolated beyond the health conditions studied here, but, provided that a detailed description of the research situation and methods is given, other researchers should be able to compare the specifics of this situation with the ones they are in and be able to transfer the results to other health conditions or some nonmedical settings where there is participation and discussion among peers of a support group. The researcher believes that similar results would be possible using newer communication technologies such as Facebook or blogs since they are similar in terms of the purpose for which health consumers use them.

To aid and improve transferability of the study findings, the researcher chose a large and varied sample population across different gender health conditions. In addition, the researcher trained and tested the ATLAS.ti software before using it. Then the software was consistently used throughout all of the coding and analysis of the data.

5.5.3. CONFIRMABILITY

As widely reported in the literature, confirmability refers to the extent to which the data and results of a study are based in the context where participants interact and not on the researcher's biases. The concept is similar to that of intercoder reliability assessment used in quantitative research. The goal of confirmability as indicated by Stommel and Wills's (2004) work is "to determine whether two or more researchers can agree on the decisions made during the study on what data to collect and how to interpret it" (p. 288).

In order to facilitate confirmability, the researcher avoided the use of more intrusive methods such as doing data collection in active threads of messages or announcing to discussion board participants that data from their posted messages was going to be analyzed. Instead, the researcher used past threads of conversations within several different online support groups. Also, the decisions made about what data to collect and how to interpret it was included in the methodology section so it can be used by other researchers that want to replicate the study.

5.5.4. DEPENDABILITY

The concept of dependability, as widely used in the literature, refers to how stable or unstable the data patterns tend to be over time. Thus, when an external reviewer examines the process of data collection and analysis executed by the principal researcher, he/she can arrive at the same conclusions.

In order to support dependability of this study, the researcher performed cyclical reviews of the coding schema that were revised by an expert on the field. The researcher also performed several intercoder reliability tests for portions of the data until discrepancies that occurred were resolved. The researcher also collected the data on multiple occasions throughout the year so there was some measure triangulation (in this case triangulation by time) that could show consistency of the data.

5.6. LIMITATIONS OF THE STUDY

Inevitably, even though researchers take measures to reduce limitations of their studies, as was done here, all studies come with some constraints. Thus, the findings of the study should be looked at in light of the study objectives and the methods used to reach those objectives. The objective of this study was to gain further understanding of how health consumers were actually using information they had received within online support groups in response to questions they asked, and whether any pattern of use emerged between the types of uses and the types of questions asked, the type of medical content being discussed, or the function of the reply messages received. Thus, the research has the following limitations:

- Since the research used a retrospective interpretative method, there is no way to prove that what the researcher understands from the data is actually what participants meant in their postings.

- The findings of this study were based only on data from threads of conversations from active participants, which means that lurkers' points of views were not included. On one hand, since the research used secondary/trade data, then no feedback from inactive users would have been present, which is also true from some active participants who also don't report use. On the other hand, the literature suggests that lurkers are not likely to report that they have received useful information.

- Because the data was retrieved from bulletin board archives, unless the discussion board participants described themselves, there was no way to learn about some of their demographic features, such as ethnicity, age, level of education, geographical location, Internet accessibility, and so on, that might have been useful for interpreting the data.

- Another limitation in terms of replication purposes would be that many discussion boards don't keep all of their archived data forever or they stop giving access to it past a certain number of years. At the same time, more recent data in the same or similar sites is available and would work perfectly if someone wanted to replicate this study results.

- According to Stone and Stone's (1990) and Bansal et al. (2010), personality traits impact how people assess their health information sensitivity. So, the more sensitive the information is perceived to be, the greater the concern the person will have about revealing it. Bansal et al.'s (2010) research also indicates that people's personal health status should also impact the amount of information they are willing to disclose. The limitation on this study was that since the data came from secondary sources, there was no way for the researcher to determine participants' level of sensitivity or their personality traits that could explain the amount of information disclosed or lack of it.

- Because of the scarcity of usefulness feedback (or low response rate) from the thread initiators toward those who responded with information, then the scope of the conclusions is also limited. This raises the question of whether reciprocity should be expected or new features should be created in OSGs to facilitate higher response feedback, since the boards still offer a larger volume of data at a lower cost than other methods.

While these findings do not conclusively indicate why people chose to share information use behaviors this way, they do show we gained more insight into the nature of the information shared, specifically that experiential knowledge is the most common type of information shared in online support groups. Results also suggest that the characteristics of the information exchanged can help show patterns of information sharing such as that people tend to disclose information uses more often when positive supportive and encouraging content is shared as opposed to more information-oriented content. Also, the content analysis of the messages showed evidence of message interactivity, which provided a sense of community expressed through feeling connected to others, identifying new possibilities, learning to avoid pitfalls, increasing or decreasing feeling, taking actions based on suggestions, and taking a more active role.

5.7. SUGGESTIONS FOR FUTURE RESEARCH

In spite of the conflicting previous results about whether there are or aren’t any differences in male and female online participation in support groups, this research agrees with (Blank, Schmidt, Vangsness, Monteiro, & Santaga, 2010) study that because of the “ever-changing nature of online communication and potentially different styles and audiences at different online sites it is important to expand past research both temporally and in relation to specific online sites” (p. 1401), to not only include a more comprehensive set of health conditions but also test with other non-health communities and newer types of social media technologies to create a broader understanding of information use, since as suggested by Khoo's (2014), “Different types of social media applications support and encourage different types of information behaviors” (p. 90).

Other suggestions for future research can be focused on possible evaluation of whether the amount of interaction by participants could affect the amount of reported information uses, or whether health information use by other communities such as minorities, different racial or ethnic populations from countries with culturally sensitive health issues, or people with special needs, would likely have unique information use behaviors.

Another possible question for future research, as noted by Wagner et al.’s (2001) study, would be to study whether the use of health information affects the demand for physician advice, or if it have an influence on patients' tendency to comply with treatments (Nupur, 2010), or whether information use evolves at different stages of a disease.

More specifically related to the findings of this study, future research should look into the nature of the NonMedical_Remarks content type in more detail since as suggested in Section 5.3.1. This nonspecific category seems to include more than just other issues.

In addition, this research agrees with Savolainen's (2001) in pointing out that future research on online support groups should be complemented with participant interviews to draw a more realistic picture of their role in health information use. Likewise, other research techniques, such as surveys or focus groups, should be used to directly ask online group participants about their information use behaviors.

CHAPTER SUMMARY

This chapter described some of the cognitive, affective, and behavioral actions that health consumers indicated they had taken based on information shared within the online support groups to which they belong. The chapter also discussed the implications of the findings as well as its limitations and suggestions for further research.

The evidence of online information use found in this research study was not as strong as expected (in part due to low reciprocity feedback as to what the information uses were). However, from the categories, a few interaction patterns seem to emerge, including that behavioral effects seemed to be more prevalent information uses than the affective and cognitive ones. Similarly, the data also shows that the sharing of personal experiences seems to help decision making in a number of different ways: clarifying one's own values, seeing new ways of thinking, or fostering the development and exercise of autonomy capabilities (Entwistle et al., 2011).

Since the study's data shows that participants of OSGs indeed take actions following advice exchanged with peers, and that content type, the function of messages, as well as question type values are not due to random sampling but are instead influenced by the types of conditions (OC, PC, and IN), then it is important to point out that healthcare professionals need to be more aware that patients are using these kind of forums and that they should help them to narrow down and possibly filter the advice they receive from those peers.

The research contributed to the understanding of activities that go beyond the information-seeking process, namely, information use, which can aid in the design and testing of web information systems, question answering services, and portals that satisfy users' needs more accurately.

The data also showed that there is a lack of reflection-based sharing which the discussion used to point out the importance that contributions within the health information area need to be more tailored to consumer-education resources and decision aids in order to increase health consumer awareness of how participation in these online communities can help them to improve their own health outcomes and quality of life as well as that of their peers.

APPENDICES

APPENDIX A: TERMINOLOGY

There are several key concepts that aid in the understanding of this study but none of them have a unique, universally accepted description.

Computer-Mediated Discourse Analysis approach: As defined by Herring's (2004), this refers to the "analysis of logs of verbal online interaction (characteristics, utterances, messages, exchanges, threads, archives, etc)" that is grounded in empirical, textual observations to investigate the processes of learning and interaction in online contexts.

Health Consumer: It refers to any person, including healthy people, patients, relatives and friends of patients, caregivers, or people with risk factors for the disease with an unsolved health concern, who expresses having taken some health-related action based on information received in online support groups to which they belong[30] (Gann, 1991).

Consumer Health Information (CHI): It refers to any health and illness information at the lay level, in this case, obtained from an online support group, which enables individuals to better understand their health and make informed healthcare-related decisions for themselves or their families (Gann, 1991; Marshall, 1992; Patrick & Koss, 1996).

Interactive Health Communication (IHC): The interaction of an individual—consumer, patient, caregiver, or professional—with or through an electronic device or communication technology to access or transmit health information or receive guidance and support on a health-related issue (Robinson et al., 1998).

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[30] Somebody belongs to a discussion group when that person is registered as a member of it.

Information Utilization: "As a whole, the literature conveys that information utilization is about people doing something with information that they have sought and gathered themselves or that is provided for them by someone else" (Todd, 1999b).[31] Todd also indicates "information utilization begins after the information is produced or created, and that information is said to be utilized when it is implemented as part of a program or directly leads to some specific decision or specific course of action."

Information Use: Taylor's (1991) defines "uses of information" as "what information does to or for the recipient and for his or her problem situation." Similar definitions include those of Wilson and Walsh's (1996) who state that information is used when it leads to changes in behavior, values or beliefs; and that of Dervin and Nilan's (1986) who conceptualize uses or helps as the ways in which people put answers to questions to work.

In this study, information use will refer to different cognitive, affective, or behavioral acts that users describe they have taken based on the information provided to them within an online support group to resolve or improve their health situation; this is consistent with Todd's (1999b) problem solving definition of information use. Based on these definitions of information use and information utilization the researcher also considers them equivalent terms and can be used interchangeably.

Chronic condition: This is a condition that develops and worsens over an extended period of time (MedlinePlus) and, as defined by Hymovich and Hagopian's (1992), "It interferes with the person's physical, social or psychological functioning" (as cited in Sidell, 1997). Also, according to Pollin

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[31] Doing something means 'instrumental utilization describing physical changes in practice and procedures, actions and outcomes as direct result of applications of information' (Todd, 1999).

and Golant's (1994), “Chronic conditions can be incapacitating or not; it may have a sudden or gradual onset; it may be fatal, potentially life-shortening, or of no consequence to one’s life span; and it may be progressive or unchanging” (as cited in Sidell, 1997). It is important to point out that severe life-threatening chronic conditions, such as cancers, and non–life-threatening conditions, such as infertility, are at two different ends of the same spectrum. As described by Newby's (1996), “At one end the ones that pose a threat to life create a sense of impending doom which affects all phases of family adaptation. At the other end, the illnesses that do not pose a threat to life must focus on long-term adjustments and stable, permanent realignment of roles.”

Appendix B: List of online discussion boards used for the data collection

Selected Infertility Bulletin Boards

Site	URL	
FertileThoughts	http://www.fertilethoughts.com/forums/ (post from various selected subgroups)	
Fertility	http://fertility.org/	

Selected Ovarian Cancer Bulletin Boards

Site	URL	
American Cancer Society (ACS)	https://csn.cancer.org/forum/132	
Ovarian	http://nocccommunity.ovarian.org/	

Selected Prostate Cancer Bulletin Boards

Site	URL	
American Cancer Society (ACSCSN)	https://csn.cancer.org/forum/126	
WebMD boards	http://exchanges.webmd.com/prostate-cancer-exchange	

APPENDIX C: CODEBOOK INSTRUCTIONS (SCHEMAS USED FOR CODING)

This variable is set as a Document family so it is **applied to each document:**

Variable	**Code values**	**When to apply this code?**
BB_Condition_community	OvarianCancer_BB_community ProstateCancer_BB_community Infertility_BB_community	The name of each document will indicate the bulletin board community to which each thread belongs to. So, use the document name to decide to which document family to assign each primary document.

The following variables are applied to **each post within each thread:**

Variable	Code values	When to apply this code?
Username	Refers to the name of the person making the post.	To assign User_Name, select just the name of the person posting each time it appears.
P01…P14	This is each participant's unique identifying number within a thread	To assign the P01…P14 code, select the whole post including the subject, the name of the person posting, as well as the post itself but not the replies information. Each participant will get a different number but each time a participant post he will get the same id number. The codes will be repeated from thread to thread so P01 will appear in thread 1 and thread 2 and so on, but they most likely will refer to different participants.
Who has the condition?	Particip_has_condition.	Code whatever sentence the participant uses to indicate that he suffers the condition (for ex. "Mine metastasized") as **Particip_has_condition.**
	Relationship_Spouse/Partner Relationship_Friends&Others Relationship_ExtendedFamily	Code whatever sentence the participant uses to indicate that he is a **partner, relative or a friend** of somebody that suffers the condition (ex. "my sister's cancer" indicates that the participant is a relative of somebody with the condition). **Extended_family** includes children, aunts, uncles, cousins, grandparents, and in-laws.
	Particip_indicates_Nobody___has_condition	Code whatever sentence the participant uses to indicate that nobody has the condition or that the information is only for homework or research purposes as **Particip_indicates_Nobody_has_condition (**Ex. I need the info for my research)

Diagnosed Condition	This will vary depending on the condition being studied.	Code whatever text indicates the type of diagnosis that the participant or somebody else was diagnosed with, which is related to the community being studied. For. Ex. Ovarian Cancer II.
Sex of the participant	Sex_Male Sex_Female Sex_Unclear	Use the complete post including the subject, the name of the person posting, as well as the post itself to code for **Sex_Male** or **Sex_Female** depending on the name. The type of condition can also help to determine the sex (ex. If somebody says I had chemo in the ovarian BB this would be a Female participant. **If you know somebody is a female** from a post, keep that information for any subsequent post in the same thread constant, even if sex if hard to tell from the subsequent post. **If the name is too ambiguous** (ex. “BrownEye,” then code as **Sex_Unclear.**

Question Types Schema: The following variable is applied to **each question asked** in within each thread:

Code values	**When to apply this code?**
QT_01_Assertion	The poster makes a statement indicating that he lacks knowledge or does not understand the information. Ex. I don’t understand what the results mean.
QT_02_CausalAntec	What state or event causally led to an event or state? Ex. What did the doctor do to prevent patient getting worse?
QT_03_CausalConse	What are the consequences of an event or state? Ex. What are the effects of taking this drug?
QT_04_Comparison	How is X similar (or different) to Y? Ex. How is chemo similar to radiation?
QT_05_ConceptCompleti	Objects/names/places/times in response to who/ what/ where/ when questions about states, events, and actions. Ex. What kind of testing do they do to determine if you have the condition?
QT_06_Definition	What does X means? Ex. What does Endo means?
QT_07_Directive	When a poster wants other participants to perform an action and is told more forcefully than a request. Ex. Call me when the results are ready.
QT_08_Disjunctive	Which one of two or more alternatives is true? Ex. Is the therapy effective for male infertility or for female infertility?
QT_09_Enablement	What object/resources/abilities/states will allows a poster to perform an action? Ex. What kind of feedback will help you make a decision?
QT_10_Example	Could you give me an example of how that treatment worked for you?
QT_11_Expectational	Why didn’t the treatment work?
	Request for the value of an attribute or for medical tests in which the features (shape, form, sound, & picture) are informing. Ex. What does the x-ray show?

QT_12_FeatureSpec QT_13_GoalOrien	Request for reasons and motives behind an intentional action. Ex. What are you going to do with the information you get?
QT_14_Instrumental	What instrument (or plan) allows an agent to accomplish a goal? Ex. What is the plan to increase my fertility and ovulation?
QT_15_Interpretation	What concept or claim can be inferred from a static or active pattern of data? Ex. What do these different PSA levels mean?
QT_16_Judgment/Eval	What value does the answer place on an idea or advice? Ex. Would that treatment be too aggressive?
QT_17_Procedural	What plan (procedure or set of acts) allows a participant to accomplish a goal? For ex. How can I lower my PSA level?
QT_18_Quantification	Request for the magnitude (how much) or frequency (how many) value of an attribute. Ex. How much time does embryo implantation take?
QT_!9_Request	The poster politely asks the other members “listening” or someone in particular to perform an action. Ex. You should make an appointment with a specialist.
QT_20_Verification	Implied yes/no/maybe/who knows answer. Also questions that on the surface appear disjunctive but they actually have only one answer. Ex. Does she have muscle pain? Is she in pain or not?

Functions of Reply messages: This schema is applied to **each post within each thread.** Since each post can have multiple message functions then select complete post as the text to code for each different function.

Code Category	Code subcategories	When to apply this code?
FM-01_Info_Seeking	FM-01.01_AsksOrientation	Asks for orientation, information, repetition, confirmation.
	FM-01.02_AsksOpinion	Asks for opinion, evaluation, analysis, expression of feeling.
	FM-01.03_AsksSuggestion	Asks for suggestions, direction, possible way of action.
FM-02_Info_Giving	FM02.01_GivesOrientation	Gives orientation, information, repeats, clarifies, confirms
	FM-02.02_GivesOpinion	Gives opinion, evaluation, analysis.
	FM-02.03_GivesSuggestion	Gives suggestions, direction, implying autonomy for others.
FM-03_Describe_Experience		Describes personal experiences with use of prescriptions, treatments, having the disease, coping, self-esteem.
FM-04_EncouragSupport		Shows solidarity, raises other status, gives help, reward.
FM-05_SocEmotional_Iss		Expresses feelings, make goodwill wishes (Congratulatory messages, Sympathy notes).
FM-06_Humor		Shows tension release, jokes, laughs, satisfaction.
FM-07_Thanks		Shows gratitude for the support, help and information received, for kindness, for listening, for being.
FM-08_Prayer		Prayers or reference to prayers are made on behalf of the information seeker/giver and their families.
FM-09_Activism		Participant invites other participants to call or write legislators, newspapers, magazines, talk shows and other similar entities as means for raising awareness

FM-10-Ack_InfoUsefulness		Participant mentions that the information was useful or helpful but he/she doesn't indicate how it was actually used.
FM-11_Ack_InfoUse	FM-11.01_Ack_CognitiveIU	Thinking affected by using information (cognitive information use) by showing agreement, understanding, concurring, complying.
	FM-11.02_Ack_AffectiveIU	Indicates emotional reactions (affective information use) by description of feelings experienced after the inform. exchanged on the online board.
	FM-11.03_Ack_BehavioralIU	Describes doing something based on the information or suggestions (behavioral information use) received through the online board by other peers
FM-12.01_Ack_NonInfoUse		Indicates that the information was not used because it did not fit the situation, it did not come at the right time, or the recipient disagreed with it.
FM-13_Board_Issues	FM-13.01_TechBoard_Iss	When technical issues with the board (including problems with posting, board not working properly) are the theme of the posting.
	FM-13.02_AdmBoard_Iss	When administrative issues with the board (including board rules not being enforced, complains about flaming, etc) are the theme of the posting.
FM-14_Miscellaneous		When the function of a message cannot be fit under any of the previous categories.

Type of Message's Content: There can be multiple types of message content in each post within a thread. Select the **complete post** and apply as many different content types as are found.

Code Category	**When to apply this code?**
CT-01_Symptoms	Description of issues that person is having (For ex. my symptoms seemed to indicate that I could have a form of XXX or YYY)
CT-02_Differential_Diagnosis	The content of the post is about any aspect of a diagnosis other than symptoms and the diagnosis itself, including examination process that leads to a diagnosis. (For ex. We try to conceive for more than a year with no results).
CT-03_Epidemiology	The content of the post discusses incidence, prevalence, spread of disease, and morbidity & mortality. For ex. Since my aunt was diagnosed with this condition, how likely is that I or my kids could have it too.
CT-04_Etiology	The content of the post talks about signs and studies related to determining CAUSES of disease and their modes of expression. For ex. Is there any evidence that asbestosis can cause colon cancer?
CT_05_Wellness	The content of the post discusses issues of public health such as effects of smoking, alcohol use, and physical activity on the condition. For ex. Has alcohol use being an issue in treating the condition.
CT_06_Medication	The content of the post discusses how drugs are use to alleviate symptoms. For ex. have you tried "X"?

CT-07_Diagnostic_Testing	Content of the post is about describing any test performed with the purpose of aiding in the diagnostic of the condition. For Ex. The doctor tested my PSA
CT-08_Pathophysiology	When the content of the post is about the functional changes that accompany a particular syndrome or disease (in other words, description of how the disease affects the body internally. This is different from symptom which refers to the signs people perceive about the disease). For ex. increased protein breakdown and glucose production are some pathological abnormalities (pathophysiology) related to some cancers. A sign of these could be malnutrition.
CT-09_Prognosis	The content of the post is about the forecasting or predicting outcomes of the condition. For ex. How much more time will she get if she does treatment “X”?; What would be a ballpark figure of survival rates on people with my condition at this age?
CT-10_Treatment/Therapy	Post discusses different types of treatments or therapies other than medication including diet, alternative treatment, physical therapy, surgical procedures, and type of treatments. For ex. Why do you think treatment “X” is the best option?
CT-11_NonMedical_Remarks	The post describes any content not specifically related to any of the previous medical subcategory aspects of a condition. For ex. What is the address to subscribe to listserv “X”?

How was Information Used? A post can contain descriptions of various uses given to different pieces of information received. Thus, code whatever sentence or paragraph that indicates the information received has been used or utilized in some way.

IU-COGNITIVE SUBCATEGORIES	**WHEN TO APPLY THIS CODE?**
IU-01.01_NewImprovedUnderstanding	Participant describes getting a new or altered more realistic picture of himself or others situations based on instructions, facts or answers to the questions he/she asked. Participant expresses being able to see the road ahead.
IU-01.02_IdentifyPossibilities	Participant expresses being able to identify possibilities.
IU-01.03_LearningManageStress	Participant realizes the importance of learning how to manage his/her condition related stress.
IU-01.04_LearningAvoidPitfalls	Participant expresses learning to avoid pitfalls about what not to do, to prevent something bad or doing something undesirable.
IU-01.05_HowInfoIsInterpreted	Participant expresses how he/she has interpreted, classified, or related the information received to existing knowledge.
IU-01.06_GettingBetterInformed	Participant indicates that a more informed decision was made about a course of action, including doing nothing.

IU-02_AFFECTIVE IUS

IU-02.01_StrengthenSelf-feelings	Participant expresses a resistant / avoidance attitude toward new information.
IU-02.02_BetterAble2Relax	Participant expresses being better able to calm down and relax.
IU-02.03_FeelingConected2_Others	Participant expresses feeling more connected to others.
IU-02.04_IncrOrDecrFeelings	Participant expresses that feelings of uncertainty, doubt, discouragement, anxiety, depression, shame, excitement, or satisfaction either appear, increase, decrease or disappear.

IU-03_BEHAVIORAL IUS

IU-03.01_Requested2ndOpinion	Upon the information exchanged in the OSG, the participant requests a 2nd opinion.
IU-03.02_TakingMoreActiveRole	Participant expresses taking a more active role because of issues discussed in the board
IU-03.03_TookActionBasedOnSugg	Participant indicates will take an action based on a suggestion given in the OSG
IU-03.04_TalkingAboutCondition	Participant expresses talking and discussing about his condition with others based on suggestions from the OSG.
IU-03.05_ChangesInLifeStyle	Participant indicates lifestyles, dietary or other changes made based on information and issues discussed in the online board

APPENDIX D: DIAGNOSED CONDITIONS REPORTED

Ovarian Cysts	Juvenile Granulosa
Chocolate Cyst	Small Cyst
Uterine Cancer Stage 1B	Stage III C epitheleal/omentum
(Bordln, low malig, malig) Ovarian Cancer (stage I, II, III, IV)	Pulmonary Embolism
ADNEXAL CYSTIC LESION	Endometrial Cancer, Endometriosis
Breast Cancer	Leukemia
(Metatastic, Terminal) Prostate Cancer (grade 9)	Prostate Cancer (in spine and pelvis)
RRP	Gleason 7 Adneocarcinoma of the right lobe
Post Incontinence	MTHFR
Enlarged Prostate	High Blood Pressure
High Cholesterol	Age factor, dermoid returned, male factor, cysts
Low/no sperm poor morphology	PCOS
Retroverted Uterus	Fibroid tumor on the back side of my uterus

APPENDIX E: CHANGES/CONSOLIDATION ON TABLES

The **relationship category** initially had 7 subcategories as listed below:

DEM-06_Relationship_Child
DEM-07_Relationship_Extended_family
DEM-08_Relationship_Friend
DEM-09_Relationship_Other
DEM-10_Relationship_Parent
DEM-11_Relationship_Sibling
DEM-12_Relationship_Spouse/Partner

These previous categories were grouped and renumbered into the following three since several of them have zero incidences in the data:

DEM-06_Relationship_Spouse/Partner
DEM-07_Relationship_ExtendedFamily (includes Parent, Sibling, Child)
DEM-08_Relationship_Friends&Others

The **FM-Coding Schema** initially had 14 subcategories as shown in Appendix C. Two of the subcategories were eliminated since they had zero incidences in the data and others were grouped, rearranged, and renumbered as follow:

Eliminated

FM-12.01_Ack_NonInfoUse
FM-10_Activism

Renumbered & Consolidated

FM-11_Ack_InfoUse changed to FM-10 FM-11.01_Ack_CognitiveIU changed to FM-10.01 FM-11.02_Ack_AffectiveIU changed to FM-10.02 FM-11.03_Ack_BehavioralIU changed to FM-10.03
FM-13_Board_Issues (Tech & Adm Board issues grouped) changed to FM-11
FM-14_Miscelaneous changed to FM-12

In the **IU-Coding Schemas**, initially we had the categories shown below

Cognitive IUs	**IU-01.01_NewRealisticPict IU-01.02_NewGeneralUnderstanding IU-01.03_SeeRoadAhead IU-01.04_IdentifyPossibilities IU-01.05_LearningManageStress IU-01.06_LearningAvoidPitfalls IU-01.07_GettingMoreConfused IU-01.08_HowInfoIsInterpreted IU-01.09_TakingActiveRole IU-01.10_BecomingWilling2Talk**
Affective IUs	**IU-02.01_IncrOrDecrFeelings IU-02.02_ResistantToNewInfo IU-02.03_StrengthenSelf-feelings IU-02.04_GotMotivated2TakeAction IU-02.05_BetterAble2Relax IU-02.06_FeelingConected2_Others IU-02.07_FeelingLessIsolated IU-02.08_Able2CopeWithLoss IU-02.09_ReliefUnwantedResponsab**
Behavioral IUs	**IU-03.01_TookInformedDecision IU-03.02_RequestedCopyMedRecords IU-03.03_Requested2ndOpinion IU-03.04_SelfMedicating IU-03.05_TakingMoreActiveRole IU-03.06_AdvocateAboutCondition IU-03.07_TookActionBasedOnSuggest IU-03.08_TalkedAboutCondition IU-03.09_ChangesInLifeStyleMade**

These previous categories were consolidated into the following since several of them have zero incidences in the data:

Cognitive IUs	IU-01.01_NewImprovedUnderstanding IU-01.02_IdentifyingPossibilities IU-01.03_LearningManageStress IU-01.04_LearningAvoidPitfalls IU-01.05_HowInfoIsInterpreted IU-01.06_GettingBetterInformed
Affective IUs	IU-02.01_StrengtheningSelf-feelings IU-02.03_BetterAble2Relax IU-02.04_FeelingConnected2_Others IU-02.05_IncrDecrFeelings
Behavioral IUs	IU-03.01_Requested2ndOpinion IU-03.02_TakingMoreActiveRole IU-03.03_TakingActionBasedOnSuggest IU-03.04_TalkingAboutCondition IU-03.05_MakingChangesInLifeStyle

APPENDIX F: EXAMPLE OF COMPLETE THREAD

****** BB –> OVARIAN.ORG Thread N-14 ******

————————————————————————————————-

CA-125 test

From: Miriam

I had the test last Friday and haven’t heard back. I am assuming no news is good news and I’m afraid to call. Do you think they didn’t call me because it was normal?

I have a HMO and they have been very nonchalant about my complaints and pain. I will have a CT scan on May 19.

Replies to this message:

- Re: CA-125 test by sonya

————————————————————————————————-

Re: CA-125 test

From: sonya

never wait to hear back from the Doctor. Always call to confirm
your test results.

Replies to this message:

- Re: Re: CA-125 test by Paul
- Re: Re: CA-125 test by Lori
- CT Scan by Miriam

————————————————————————————————-

Re: Re: CA-125 test

From: Paul

Sonya is right being proactive pays...
Paul

Replies to this message:

- Re: Re: Re: CA-125 test by Miriam

________________________________-

Re: Re: Re: CA-125 test
From: Miriam

I just called and they have a 1-800 where they post test results. There was nothing in mine. I left a message for the doctor.

________________________________-

Re: Re: CA-125 test
From: Lori

Miriam, Not only can you (and should you) call the doctor, but if you went to a separate lab or hospital to have the blood work done, you should be able to go there and show some picture ID, and pick up a copy of the results yourself. If you do this, ask them to show you which number or column shows your lab result. (I did this, and there was a big difference between my result (4) and their technician's encoded ID number (243)- their method of telling who drew the blood!) I give my doctor's office 2-3 days, then I call them. It's very possible that for you, no news is good news, but just in case, be proactive! Besides, then you can quit waiting and wondering, and that peace of mind is worth alot!

All the best, Lori
________________________________-

CT Scan
From: Miriam

Doctor said my CA-125 test was fine. I just had the CT Scan yesterday. How long did it take you all to get your results? I'm a little anxious.
________________________________-

**** BB –> FertileThoughts.com Thread N-33
————————————————————————-

Deva

worried about fertility
Hi,
I found this site whilst looking for articles on infertility.
My partner and I have been trying for a year without any result.
I know i shouldnt worry too much because we have missed a couple of fertile times, so i guess i can wait a little longer. But still... It’s like i can sense something is wrong.

I know for a fact we’ve made love at least 5 times during the fertile time.
I also feel very stupid because when i stopped taking the pill, i told quite a few of my friends: my best old friends, two rather new friends, my old buddy from university etc... I was so excited that we decided to stop the pill, to me it was almost like being pregnant!Now i realise how stupid i’ve been, and i feel very shame-faced. People havent started asking anything, but i’m always scared they will. My partner is also a bit angry with me for telling our friends.
I keep thinking: what if we cant have a baby? All my friends have babies now, even one friend whom i thought would be the last one. When she told me it was a real blow, though i didnt let it show. I didnt even know she was trying. It took her one and a half month to conceive...

I cant help wondering how i would react if infertility is confirmed. I’ve always thought i would be a mother some day. Also, there is really no one i can talk about this to, so that’s why i’ve come here. Maybe all i need is a reality check: it’s only been a year, plus a we’ve had a few very stressful months due to family problems. So there’s been a lot of stress. But i’ve read that psychological causes are not really serious...?

Anyway, thanks for reading!

Deva (ps i’m 31 yrs old)

———————————————————————————————————-

jrob

I’m 31 too. I totally understand the stress & things going through your mind. I think reading some of the stories on this forum have even made my fears stronger. Hearing about other’s struggles makes you realize that such problems are real and not in your head. My hubby & I have not told anyone. I kinda wish we had told people when we first started trying. At least there would be some support system of people knowing that we were trying, but going through some difficulty. People are understanding. That’s probably why you haven’t been asked. On the other hand, because no one knows that we’ve been trying, I get comments all the time. I just want to scream, “I could be pregnant right now”!! But I don’t, because I know that the likelihood is that I’m not. I can’t imagine what it will feel like to one day see the plus sign on the home test. Like you, I hope I get to find out. Hang in there.

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Deva

thanks for reply!

Hi!

thanks for your reply. It feels really good to know someone can relate. It’s exactly how i feel: thoughts “racing” through my mind, always torn between “i’m exagerating” and “something’s wrong.” Like i never know what the truth is!

About what you said: why dont you tell a couple of really close friends? Just so that you’d feel less distanced from them. Then again, i think that it’s also a risk, because you cant tell how they’ll react. In my case, i told my very best friend who is a gay man, and i cant talk to him about it because he is now struggling with his own issues coming to terms with not having children. So, i sense that for him, my “problem” is not as “big” as his. It’s very sensitive.

Also, another friend of mine keeps telling me it’s probably in my head, that we werent really ready for a baby, and i was offended by her remark about my couple.

How long have you been trying? I still think it’s because we’ve missed the fertile times a few times. But maybe i’m fooling myself, i really dont know (we started out real easy without calculating the exact time, but it’s always at the back of my head).

Anyway, i wish you lots of luck and thanks again
deva

Cel
Hi and welcome to the site!

I remember that first cold pit in my stomach when I first began to suspect IF problems. And I can relate to your concerns about telling friends. You never know how they will react to your fears. I found, unfortunately, many friends were not very understanding. Mostly because they couldn’t relate; they all had children. But of course, you have to decide what works best for you when discussing your concerns with friends and family.

I’m taking a guess that you are overseas.... Because the health care system is
different there, you may want to research when you can seek medical advice for your concerns. If you need to be on a waiting list, or there’s a time period to wait before seeking testing or tx, find that out now instead of when you are actually looking to get help. There are some low tech things you can do to check out your situation. Try ovulation predictors or basal body temperatures (BBT) to determine if you’re ovulating.

A good book to read, not just for BBT info, but also for a lot of good information about your body and other fertility signs, is Toni Wechsler’s Taking Charge of Your Fertility. Also, if it’s possible, your partner should get a semen analysis (again not sure if that is possible if you are in another health care system).

Stress can affect fertility, so that may have impacted you over the past year.

Take care,
Cel
———————————————————————————————————-

bailymk

Hi! My story is very similar to yours. I am 32 (just turned) and we've been trying for 14 months. I just had this gut feeling that I was going to have problems getting PG and I was right. After all the tests, we found a slight CM problem but it's pretty inconclusive. Especially since I landed up pregnant last month but then miscarried (without any treatments to combat the CM issue).

So...we are on clomid and our first IUI this month. We'll find out soon if it worked (fingers crossed). Some days I could just cry all the time and other days I feel ok and positive that it will happen for me when the time is right. I just hope it's soon! 8-)

One thing is for sure...I don't know how I would survive without this site. IF is such a hard thing to talk about with people that can't relate. I only found this a few months ago but it's been a savior!

Good luck and I hope your battle with IF is very, very short.

Melani
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Bonnie2

Hi Deva,

I am impressed you remember who you told you were ttc. I blabbed to sooo many friends and family members, I can’t keep up! Now I catch myself feeling irritated when they ask. I know it is absurd for me to feel that way...but isn’t it rude to ask, dammit!?

I have been ttc for 1 year & clomid doesn’t make me OV. Anyway, just thought you would feel better knowing that there is another woman with a bigger mouth than yours.

Good luck and take care!!
____

Deva

thanks for replies
Hi there!

I’m not sure how to reply to each one of you seperately, so that’s why i’m posting one group reply!

Thanks for taking me seriously.Though i dont really consider myself infertile just yet!, my thoughts and concerns are very real.

Thanks for the tips for low tech analysis. I guess that would be a good start. Because i’m getting impatient and would like to get some sort of “answers” or feel like i am taking control...

I’ll also check out the book if i can find it. Yes you were right i am from overseas (Switzerland in fact). But for some reason there are not many support sites in my language.

I’m sorry to hear about the miscarriage, I’m sure it must have been really tough. But I’m sure you will get pregnant soon again and then it will be fine. I heard that happens quite often and is not necessarily a sign of IF. Good luck to you! I chuckled when i read your answer saying you had a bigger mouth than me! In fact, i usually am rather secretive, but this was just something so overwhelming (stopping the pill) that i just couldnt help myself. In a way, i think, who cares, i did what felt right at the time and that’s it.

One last thought: how do you feel about so called “psychological” obstacles to getting pregnant? I read on some sites that it’s humbug, yet no later than last night i met a business colleague of my partner who’s ex wife specialises in treating women who want to get pg. Apparently, some “realize” during the therapy that they dont want kids, while others overcome some kind of obstacle that keeps them from getting pg. I’m not sure what to make of it, but it is intriguing to me for various reasons: sometimes i feel like my own Mum doesnt want to be a grandmother (she even told me so once), plus i am doing a degree at university and got one year left, so at times i feel guilty about wanting a baby now (it’s been building up for years!) when I “should” finish my degree first... Can you relate to this? Sometimes i feel like i am not “allowed” to have a baby.

Anyway, i’ll stop babbling! thanks again and all my best thoughts to all of you
love, Deva
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****** PC —> WebMD.com Thread N-7 ******

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Recurrence. Is it systemic?
by curtisbks, on 10/4/2004 12:57:19 AM

I had RP 12-16-03. For 18 weeks prior to that I was in a clinical trial, Lupron, Taxotere, and Gleevec. The lowest PSA before surgery was 0.2. After surgery PSA at 6wks & 3mos. was undectable. At 6mos. 0.2. At 9mos.on 9-16-04 0.6. Cat & bone scans negative. I am now back on the Lupron homone wagon.Uro at MDA thinks it is systemic. I did have clear margins and 1 node involved.

After some reflection, my question is this, if it is or was systemic why was the PSA undectable after surgery? The right nerve bundle was spared. I have a feeling it still may be local. Maybe just wishful thinking. As always any input from the board will be appreciated.

Curtis

*   Re: Recurrence. Is it systemic?
by az4peaks1, on 10/4/2004 4:42:00 AM
o   Re: Re: Recurrence. Is it systemic?
by neutrondbob, on 10/4/2004 8:05:18 AM
*   Re: Recurrence. Is it systemic?
by MANUELPM2, on 10/4/2004 11:26:11 AM
o   Re: Re: Recurrence. Is it systemic?
by R_and_J, on 10/4/2004 1:48:54 PM
*   Re: Recurrence. Is it systemic?
by Richards5150, on 10/4/2004 1:41:15 PM
o   Is it all systemic???
by R_and_J, on 10/4/2004 8:51:44 PM
o   Re: Is it all systemic???
by curtisbks, on 10/5/2004 1:57:51 AM
o   Re: Re: Is it all systemic???
by DonnaScott16445, on 10/5/2004 4:10:21 AM
o   Re: Re: Re: Is it all systemic???
by R_and_J, on 10/5/2004 8:11:52 AM

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* Re: Recurrence. Is it systemic?
by az4peaks1, on 10/4/2004 4:42:00 AM

Hi Curtis,- Of course there is NO way that I can know whether you are systemic or not, but you certainly have a number of factors that, in my layman's opinion, would make that statistically probable.
They include:
(1) Lymph Node involvement found at the time of surgery.
(2) That "undetectable" PSA levels (less than 0.2 ng/ml) were limited to only 3 months or less post-operatively.
(3) This, in spite of the fact that you had 18 weeks of chemical intervention immediately prior to surgery, the residual of which could have potentially depressed the earlier post-op PSA readings.
(4) The MDA specialist seems to think so and he has far more information, knowledge and training to make that judgment than anyone here.

I believe that all of the above factors would be considered as increasing the statistical likelihood of systemic disease, rather than a local recurrence. I repeat, however, that I am a layman and would strongly urge you to follow the findings and advice of the professionals at MDA, which I am assuming is M D Anderson. For your own peace of mind and confirmation, you might consider asking for a referral to a Medical Oncologist on their staff, for consultation, if that has not already occurred. Good luck and God bless!- John
(aka)xxxxxxxxxx@sssss.ccc

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* Re: Re: Recurrence. Is it systemic?
by neutrondbob, on 10/4/2004 8:05:18 AM

I am a lay-lay person and can only speculate, but seemingly is somewhere creating psa detectable levels. Dr. Barken had a written piece in the Paact Newsletter a few months ago, about micro-metastesis and possible recurrence even in a RP patient at 10 years out, although probably much rarer situation for patients in general. It seems that the rule book for PCa is far from ink on the pages.

N-Bob (hang in there brother)

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* Re: Recurrence. Is it systemic?
by MANUELPM2, on 10/4/2004 11:26:11 AM

Hi curtisbks.

you say:
“After some reflection, my question is this, if it is or was systemic why was the PSA undectable after surgery?”

Undetectable is an relative concept.
It only means that they cannot detect very tiny amounts of PSA below a certain level (<0.003ng/ml with the most sensitive PSA assay).
You can even reach that PSA nadir (below 0,003)and still have a recurrence (local or systemic) some years afterwards.
Now there seems to be an agreement on considering undetectable, for functional purposes (whatever the hell that could mean), a value of less than 0.01 ng/ml.
Further, PSA is no longer considered prostate specific, since it has been found in other tissues than the prostate and in females (although in very low amounts).

Wether the recurrence is systemic or not no one can tell. They can just guess on the basis of your digest and statistical data.

There is still time to try adjuvant External Beam Radiation, but you have to be aware that It could be of no use and it may have side effects.
On the other side, there are recent reports stating that adjuvant EBR can be of benefit, even for N+ patients.
Doctors still do not agree on almost every aspect of PCa.
You can seek for other opinions and then you’ll have to decide on what doctor’s opinion you find more reliable or convenient.
They don’t even agree on the potential value of early adjuvant Hormone

Therapy (your case and mine).
Don’t be afraid to consult an oncologist. It doesn’t mean you’re assuming a systemic condition.

My best wishes.

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*   Re: Re: Recurrence. Is it systemic?
by R_and_J, on 10/4/2004 1:48:54 PM

Hi Curtis,
I’m with Manuel and John on the Medical Oncologist idea. I think it would be helpful to talk to someone who is trained in looking at the ‘bigger picture.’ While Med Onco’s do specialize in ‘medical’ treatment modalities, I have heard that they tend to have a less biased approach to particular treatments. I do have to tell you that you are very lucky to be at MDA. I met a guy who had treatments at the MDA in Orlando and he was extremely satisfied with the ‘consultative’ approach to his case. They put his case up at their regular ‘prostate group’ meeting and debated amongst themselves about the best way to treat his recurrence (8 years post-op). He felt that he got 5 second opinions right on the spot!

As for your case, it might help to have more stats... ie, your

age, any issues with ED since the surgery, etc. I get concerned when a relatively young person chooses radiation (especially if you have one nerve left), because there have been some recent longitudinal studies published about the effects of radiation 5 years out (I think one was posted on this board about 2 weeks ago). I actually heard a very controversial statement from a Uro that we consulted last week who adamently stated that ‘radiation should be banned in the treatment of prostate cancer’ — of course he is a surgeon ;-)

If you are interested in looking into the hormonal treatments for recurrence, try the PCRI website at www. prostate-cancer.org

— it is pretty balanced. I met the FL liaison for PCRI at a conference and she was very helpful.

Best of luck with your decision making.
Rondi

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*   Re: Recurrence. Is it systemic?
by Richards5150, on 10/4/2004 1:41:15 PM
Dear Curtis,

I agree with everything said in the previous responses to your post. Most importantly, the need to see a Medical Oncologist. The rapid PSA doubling time, would, in my lay opinion indicate that the PCa is systemic and warrant the Lupron. Please put your mind at ease. There is no way to know at this time in absolute terms if the PCa is systemic or not. The same thing happened to me. I simply considered the Lupron restart as insurance. You are being treated at one of the NCI designated National Cancer Centers. You have some of the top docs in the U. S. If anyone would like to find one of these Cancers Centers, you can find their locations at:

http://www3.cancer.gov/cancercenters/centerslist.html

Lupron is generally easily tolerated. The main side effects that I have are a general nervousness, which a beer or anti-anxiety tablet alleviates and hot flashes. If the hot flashes become intolerable for you, there are drugs that you can take to alleviate this also. Megace, for example. Your docs can help you with these side effects if they become intolerable for you.

A word about long term use of Zoladex or Lupron: A serum testosterone test is usually done periodically to make sure that the drug is working i.e., that the testosterone is at castration level (generally considered to be 20 or below). Additionally, bone density studies are needed periodically to monitor the condition of the bones as these drugs some how lead to Osteoporosis in some, but not all cases.

A word about having salvage radiation treatment. Please get lots of opinions before you consider this. Radiation carries its own package of unpleasant side effects. Most important, it must be absolutely confirmed that the disease has not spread to distant parts of your body. It will not achieve anything to burn down the barn and the horses still in it, if some of the horses have left the barn.

Please note: I am not a doctor. Additionally, I am not one of the many experts that are on this board. If I have given you any incorrect info, they will back me up.

Please be happy and go on with your life. Whether or not your PCa is systemic, you are going to have many great years ahead of you.

Lastly, although my PCa recurred, my case has nothing what so ever to do with yours. There are no two people 100% alike, and in that same sense there are no people whose PCa is 100% alike.

Life is Good!
Richard

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*   Is it all systemic???
by R_and_J, on 10/4/2004 8:51:44 PM

Curtis,
Richard has given you some very sound information to which I would like to add just one more point for you to ponder.

There is a school of thought among some PCa researchers that all PCa is systemic and that it only ‘acts’ localized in its earliest stages.
 I heard Dr. Mark Moyad (U Mich) speak recently at a conference and then cornered him for a two hour discussion on this subject. He has written numerous articles on the subjects of nutrition & PCa, and he has written a couple of books on the subject of advanced PCa (not that you’re headed that way). You can Google his name and come up with some very interesting stuff. These are

two of his books: “The ABC’s of Advanced Prostate Cancer” by Mark Moyad, MPH and Kenneth Pienta, MD. Sleeping Bear Press, 2000 and “The ABC’s of Prostate Cancer” by Joseph Oesterling, MD and Mark Moyad, MPH. Madison Books, 1997.

Dr. Bob Leibowitz is another advocate of this theory. As is, Dr. Ron Wheeler. (Both Google-able)

When I started to research this subject, the board jumped to the fore and provided me with a ton of links. Here is the thread (just copy and paste it to your browser):
http://boards.webmd.com/message.asp?message_id=7613135

I reitterate my best wishes for your decision making process.
Rondi

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* Re: Is it all systemic???
by curtisbks, on 10/5/2004 1:57:51 AM

Rondi,thanks to you and everybody who replied. You asked about background. Age now 54. Prior to treatment PSA 8.2, GS 8, SV+. Post surgery, have ED & 98% continent.

Great info & opinions from everyone. That is what I needed. I know I should probably ask a ? like that of the docs first but feel better doing it here initially. Kind of clears the fuzz out of my brain. The guys at MDA are not real chatty sometimes. I have a good local onco as well. Will visit him soon. Thanks again to all. Later.

Curtis

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* Re: Re: Is it all systemic???
by DonnaScott16445, on 10/5/2004 4:10:21 AM

Hi Curtis-

I know what you mean about how docs aren't necessarily chatty! I think it's because they only tell you things as it comes up, so they can save time and get in all their appointments. It drives me crazy. I started faxing my Dad's Uro some questions, because that was the only way I could get them all out. I couldn't ask him during appointments because it was awkward or something. So I faxed them and he'd call me back with the questions in front of him and answer them for me. It saved him time and it helped me get my answers. (Of course he probably hates me but who cares!)

Anyway, I'm glad you have a good onco. My Mom's onco is probably the only doctor I've met that I actually trust. That's so important. So it's good you have him. And remember what someone above mentioned that systemic or not, you will be fine for many years to come. They just need to try and figure out the best treatment for your individual case. I know it might feel depressing to think of getting more treatment because you've already been through enough. But maybe it won't be so bad.

And who knows, one day we could all wake up to some big news story on CNN about a new treatment for PCa. There are many scientists and pharmacuetical companies working on that as we speak. There is a rush to find better treatments. It's only a matter of time before someone discovers a breakthrough.

Take care and let us know what your onco says.

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* Re: Re: Re: Is it all systemic???
by R_and_J, on 10/5/2004 8:11:52 AM

WOW, Curtis, you are so young—like too many others on this board who are suffering from what most people think is an 'old man's' disease.

Dr. Leibowitz has a good letter/article you should read, called

"Why am I the only one you are afraid to believe?" I believe that you can find it on the prostatepointers website. It might just get at the heart of your questions, and it would certainly be an interesting 'discussion-starter' with your onco doc. I'll try to hunt up the exact URL and post it here later today.

Rondi
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APPENDIX G: INTERCODER RELIABILITY COMPUTATIONS

INTERCODER RELIABILITY AGREEMENT FOR CONTENT TYPE CODES (CT CODES)

	Marginals		Product of Marginals	Sum of Marginals	Joint Marginal Proportions	Square of Joint Marginal Proportions
	PI	Coder	AxB	A+B	p_i	(p_i)^2
Diagnosis	16	13	208	29	0.055555556	0.00308642
CT-01	5	4	20	9	0.017241379	0.000297265
CT-02	1	1	1	2	0.003831418	1.46798E-05
CT-03	1	1	1	2	0.003831418	1.46798E-05
CT-04	0	0	0	0	0	0
CT-05	42	42	1764	84	0.16091954	0.025895098
CT-06	45	45	2025	90	0.172413793	0.029726516
CT-07	4	3	12	7	0.013409962	0.000179827
CT-08	10	7	70	17	0.03256705	0.001060613
CT-09	67	65	4355	132	0.252873563	0.063945039
CT-10	48	46	2208	94	0.180076628	0.032427592
CT-11	31	25	775	56	0.107279693	0.011508933
	270	252		522	1	0.168156662

PA_o= 0.965517241

PA_e= 0.168156662

Reliability= 0.933333333

K_CT= 0.958546571

INTERCODER RELIABILITY COMPUTATIONS

Intercoder Reliability Agreement for Function of Messages codes (FM codes)

	Marginals		**Product of Marginals**	**Sum of Marginals**	**Joint Marginal Prop**	**Sq of Joint Marginal Prop**
	PI	Coder	AxB	A+B	p_i	(p_i)^2
FM-01.01	28	28	784	56	0.079207921	0.006273895
FM-01.02	2	2	4	4	0.005657709	3.20097E-05
FM-01.03	9	5	45	14	0.01980198	0.000392118
FM-02.01	35	28	980	63	0.089108911	0.007940398
FM-02.02	23	14	322	37	0.052333805	0.002738827
FM-02.03	30	27	810	57	0.080622348	0.006499963
FM-03.01	83	85	7055	168	0.237623762	0.056465052
FM-04	67	57	3819	124	0.175388967	0.03076129
FM-05	22	15	330	37	0.052333805	0.002738827
FM-06	4	4	16	8	0.011315417	0.000128039
FM-07	27	26	702	53	0.074964639	0.005619697
FM-08	24	11	264	35	0.04950495	0.00245074
FM-09	0	0	0	0	0	0
FM-10	1	3	3	4	0.005657709	3.20097E-05
FM-11.01	9	5	45	14	0.01980198	0.000392118
FM-11.02	7	3	21	10	0.014144272	0.00020006
FM=11.03	12	9	108	21	0.02970297	0.000882266
FM-12	0	0	0	0	0	0
FM-13.01	1	0	0	1	0.001414427	2.0006E-06
FM-13.02	0	0	0	0	0	0
FM-14.	0	1	0	1	0.001414427	2.0006E-06
	384	323		707	1	0.123551312

PA_o=2A/(n_a+n_b) PA_E= Sum (pi^2)

PA_o= 0.913719943 PA_e= 0.123551312

Reliability= 0.841145833 K_FM= 0.901557207

INTERCODER RELIABILITY COMPUTATIONS

Intercoder Reliability Agreement for Information Use codes (IU codes)

	Marginals		Product of Marginals	Sum of Marginals	Joint Marginal Prop	Sq of Joint Marginal Prop
	PI	Coder	AxB	A+B	p_i	(p_i)^2
IU-01.01	2	2	4	4	0.0625	0.00390625
IU-01.02	3	3	9	6	0.09375	0.008789063
IU-01.03	1	1	1	2	0.03125	0.000976563
IU-01.04	3	3	9	6	0.09375	0.008789063
IU-01.05	0	0	0	0	0	0
IU-01.06	1	1	1	2	0.03125	0.000976563
IU-01.07	1	1	1	2	0.03125	0.000976563
IU-02.01	2	2	4	4	0.0625	0.00390625
IU-02.02	0	0	0	0	0	0
IU-02.03	0	0	0	0	0	0
IU-02.04	3	2	6	5	0.078125	0.006103516
IU-02.05	2	2	4	4	0.0625	0.00390625
IU-03.01	0	0	0	0	0	0
IU-03.02	2	1	2	3	0.046875	0.002197266
IU-03.03	14	12	168	26	0.40625	0.165039063
IU-03.04	0	0	0	0	0	0
IU-03.05	0	0	0	0	0	0
	34	30		64	1	0.205566406

PA_o=2A/(n_a+n_b) PA_E= Sum (pi^2)

PA_o= 0.9375 PA_e=0.205566406

Reliability= 0.882352941 K_IU= 0.921327597

INTERCODER RELIABILITY COMPUTATIONS

INTERCODER RELIABILITY AGREEMENT FOR QUESTION TYPES CODES (QT CODES)

	Marginals		**Product of Marginals**	**Sum of Marginals**	**Joint Marginal Proportions**	**Sq of Joint Marginal Proportions**
	PI	Coder	AxB	A+B	p_i	(p_i)^2
QT_01	3	2	6	5	0.034722222	0.001205633
QT_02	0	0	0	0	0	0
QT_03	2	2	4	4	0.027777778	0.000771605
QT_04	0	0	0	0	0	0
QT_05	12	14	168	26	0.180555556	0.032600309
QT_06	3	3	9	6	0.041666667	0.001736111
QT_07	1	0	0	1	0.006944444	4.82253E-05
QT_08	1	1	1	2	0.013888889	0.000192901
QT_09	1	1	1	2	0.013888889	0.000192901
QT_10	0	0	0	0	0	0
QT_11	4	4	16	8	0.055555556	0.00308642
QT_12	1	0	0	1	0.006944444	4.82253E-05
QT_13	0	0	0	0	0	0
QT_14	1	0	0	1	0.006944444	4.82253E-05
QT_15	1	1	1	2	0.013888889	0.000192901
QT_16	2	1	2	3	0.020833333	0.000434028
QT_17	2	3	6	5	0.034722222	0.001205633
QT_18	3	3	9	6	0.041666667	0.001736111
QT_19	7	7	49	14	0.097222222	0.00945216
QT_20	30	28	840	58	0.402777778	0.162229938
	74	70		144	1	0.215181327

PA_E= Sum (pi^2)

PA_o= 2A/(n_a+n_b)

PA_o= 0.972222222

PA_e= 0.215181327

Reliability= 0.945945946

K_QT= 0.96460612

INTERCODER RELIABILITY COMPUTATIONS

INTERCODER RELIABILITY AGREEMENT FOR DEMOGRAPHIC CODES (DEM CODES)

	Marginals		**Product of Marginals**	**Sum of Marginals**	**Joint Marginal Prop**	**Square of Joint Marginal Prop**
	PI	**Coder**	**AxB**	**A+B**	**p_i**	**(p_i)^2**
DEM-01	12	12	144	24	0.042857143	0.001836735
DEM-02	89	89	7921	178	0.317857143	0.101033163
DEM-03	0	0	0	0	0	0
DEM-04	28	28	784	56	0.1	0.01
DEM-05	1	1	1	2	0.003571429	1.27551E-05
DEM-06	0	0	0	0	0	0
DEM-07	0	0	0	0	0	0
DEM-08	0	0	0	0	0	0
DEM-09	0	0	0	0	0	0
DEM-10	6	6	36	12	0.021428571	0.000459184
DEM-11	2	2	4	4	0.007142857	5.10204E-05
DEM-12	20	20	400	40	0.071428571	0.005102041
DEM-13	70	72	5040	142	0.253571429	0.064298469
DEM-14	35	35	1225	70	0.125	0.015625
DEM-15	17	15	255	32	0.057142857	0.003265306
	280	280		560	1	0.201683673

PA_o=2A/(n_a+n_b)

PA_E= Sum (pi^2)

PA_o= 1

PA_e= 0.201683673

Reliability= 1

K_DEM= 1

APPENDIX H: EXAMPLE OF THREAD DRIFT

Can ovarian cancer actually be cured?

OC_DriftExample_seed

My mum got diagnosed feb this year, and was set to have 6 sessions of chemo, surgery then another 6 sessions of chemo. After her first 3 chemo sessions she was told she could have her surgery which was done this tuesday. surgeon said he thinks he got all of the cancer out, and that he was very pleased with how it went. She will have another 3 sessions of chemo starting in another few weeks time. She is doing absolutely brilliant.

Could she be cured or does it always come back!

OC_DriftExample_P01

I was told that 80% of the time it comes back. My surgeon was very pleased at removing 95% of the cancer (is it just me or is that the % most patients are told?) and had chemo to eradicate any lingering cells. He still could not tell me it won't come back.

OC_DriftExample_P02

OC_DriftExample_P01: I think surgeons might say a lesser percentage but I have never heard anyone say their surgeon told them a higher percentage. One thing that is interesting about ovarian cancer is that the survival rate has a lot to do with "optimal debulking"—the skill of the surgeon in removing as much of the cancer as possible on the first surgery. If that's the case, I'm screwed because 95% of the cancer grew back within weeks after surgery for me!

So if you find me shoving garlic up my nose or chanting under the full moon, you'll have to realize that I'm working on maximizing the placebo effect. Hahahahaha!

OC_DriftExample_seed : to answer your question—yes, it can be "cured" (doctors will say "no evidence of disease" or "inactive cancer") but only about 20% of the time will women live cancer free until they die of something else & no, it doesn't always come back—it often comes back—and if it does, there's a 50% chance of going into a second remission. Ovarian cancer is now being treated as a chronic health condition where women live for many years with it going on and off chemo while they wait for a better treatment to be discovered.

Here's what you don't want to hear but it's the reality of the disease: More women are dying from ovarian cancer or the complications of chemo than not.

OC_DriftExample_P03

I think that when we think of a "cure," we think in terms of the cancer NOT coming back at all. I am a 4 year survivor and I did recur, although I was NED (no evidence of disease) for a good 8 months. I do, however know a few people who never recurred and that was 8, 10 and 12 years ago. And I know there are many more out there, but once they are NED, they leave the cancer support circles and we don't hear from them. Can we call them cured? I guess the question is, "How many years does one go NED to be called "cured"??? In the medical circles, 5 years is a marker, and if you do go 5 years, you no longer need to go for checkups. (My doctor continues to have his patients come in, even after they are NED for 5 years, at least once a year.)

Wishing you and your mom the best!!!

OC_DriftExample_P04

Hi OC_DriftExample_P03,
My doctor was having me do the ca125 every 6months. I had been cancer just shy of 5yrs. My ca125 test jumped from 8 in Dec 2010 to 145 in Jan 2011. Had a ct scan and more blood work then doctor started me on Carbo March 25th, 2011. I will have a total of 8 treatments. How I used to pray that this horrible disease was gone from my body forever. Like I told my minister, didn't do much good.

OC_DriftExample_P05

My doctor does CA125 tests every month for the first year you are NED, then every 3 months (I talked him into every 60 days) until you reach 2 years. After that, every 6 months, and after 5 years, once a year. He does periodic CT scans, as well.

And he does have at least one patient who has gone over 10 years with no recurrence, ever. She was staged at IIIc, too. She is a member of my local support group and a super nice lady. She won't call herself "cured," however. She is still very anxious about the possibility of it coming back.

Another member of our local group died a few months ago, after 12 years of off and on chemo. She died from complications of the treatment. She had so much chemo; it finally took its toll on her body. Even when it's caught early, it can come back.

OC_DriftExample_P06

OC_DriftExample_seed ,
The numbers are just that...statistics. Your mum is an individual, not a statistic. And she's doing brilliantly. I suggest you and she focus on her success and the fact that some patients are, in fact, cured. Worrying about the possibility of a reoccurrence will accomplish nothing but stressing you out. I say, keep up with the monitoring, but believe that she is cured. You have nothing to lose, and everything to gain.

OC_DriftExample_seed

thankyou every-one for your comments!!

My mum and i are absolutely sooo chuft over the results so far, and i was thinking and still believe she will beat this nasty disease, i think its just when you go and search ovarian cancer on the net you don’t get very good feedback. A lot of the info seems to be very negative compared to other cancers.

my mum and everyone on here are beating it. Like everyone-else i just want her to be back to normal- cancer free!

OC_DriftExample_P07

Well, my doc was big on using the word “Cured!” Never trusted that. And, yes, he could very well be right...that I was “cured” of that particular cancer it has been five years now. But every day I worry that it or another cancer will turn up. The chemo they gave me causes other cancers. Is what it is, but I won’t let it get me down. 🙂 I hope your mother comes thru cancer free but “back to normal” it won’t be. Cancer is life changing. How many of us are the people we were before we got cancer? I know I’m not. It’s not a bad thing, I’m just different somehow, I prefer more peace in my life now, and being a caring human being is more important to me then it was before. Many blessings to your mom and family. :)

OC_DriftExample_P08

Both my surgeon and my onc told me that I have a 50% chance of being “cured.” You cannot know if you are cured until you die and the reason is not cancer. Due to my my optimal surgery, no visible tumors left, my age 46, my overall health, and IP/IV chemo they think I have a good chance of not recurring. Also since CA 125 was normal 6 after my 3 rd treatment my onc just told me I am not considered a high risk of recurring. I hope is not coming back!

OC_DriftExample_P09

Yes. As far as I am concerned I believe it can be. I know a lady who was diagnosed very early and she is living after 20 years with no other cancer experienced. A man in our church told my husband that his wife was diagnosed and given a bad prognosis and is still living after 20 years. I was also told of a lady that was diagnosed with advanced disease and had much treatment and lots of surgeries but is still living after 20 years. Granted they are in the minority but they give us hope! When I was diagnosed with PPC (peritoneal cancer which is like ovarian) I asked the chemo nurse (with 41 years experience) if they had any other PPC patients who lived 20 years and she said “yes and longer” We must all chose to be in the minority and prove the statistics wrong! Here’s to 20 more years for all of us!

OC_DriftExample_P10

OC_DriftExample_P09,

I love your attitude! I'm with you! 20 more years! And, I'm trusting as a single lady that one day I will have my own family!

OC_DriftExample_P11

I'm glad you asked your question. The responses you received gave me a boost. I love to hear survivor stories.

OC_DriftExample_seed

i love survivor stories. Actually my second cousin had ovarian cancer 11 years ago ,when she was 32 and has had no reoccurrence! The only difference between her and my mum is that her cancer was found earlier and was contained within the ovary, she did not need chemotherapy. Can ovarian cancer run in families?..the macmillian nurse told my mum this type does not , but i read differently. I think everyone on here is doing brilliant, you've just got to keep positive and keep on smiling :0)

OC_DriftExample_P06

Yes, ovarian cancer can run in families. There are at least two known genetic mutations that predispose their owners to ovarian, as well as other types of cancer. Your mum, and even you, can be tested for the BRCA-1/BRCA-2 mutation. I had the test done after my diagnosis, and insurance covered the cost.

OC_DriftExample_P13

Hi OC_DriftExample_seed ...How is your mom now?? ...My mom has been diagnosed with ovarian cancer ..I dont know which stage it is but she' s gonna take 3 chemo sessions and then a surgery !! ....

OC_DriftExample_P14

CHEMOTHERAPY OR VEGETABLE DIET?

hello. I am OC_DriftExample_P14, living 21years with my happy family, with 2 siblings, my mom and dad in the Philippines and unfortunately, that happy thingy became not that normal to us nowadays because of ovarian cancer diagnose, stage 4 in my mom and diagnose 17cm tumor in her ovary :(she's my mom! the most important person in a person's life, right? i am the eldest in the family and my dad is at Qatar, working as an OFW(overseas Filipino workers,) Filipino so-called. We don't know what to do to her situation. I don't know if I will take her life at risk because we all know that chemo will going to weaken her life and we are all afraid if it will going to lengthen her life span or not, some suggests that it would be better if we go on vegetarian diet. PLEASE HELP US! ANY SUGGESTIONS TO HER SITUATION. WILL I GOING TO BRING HER TO HOSPITAL FOR CHEMO OR NOT? THANK YOU SO MUCH. :(

OC_DriftExample_P15

Hello and welcome OC_DriftExample_P14

I am sorry about your mom’s diagnosis and that in your young age you are faced with caring for a seriously ill parent. Ultimately it is your mom’s decision, not yours. For the majority of women first line chemo will result in remission that could last for years. Chemo is difficult and has serious side effects, but sure beats the alternative. Vegetarian diet is not a treatment option; it will not cure stage 4 ovarian cancer, but probably will not hurt your mom and could be a positive lifestyle change. Without knowing the details of your mom’s situation I can only suggest following the doctor’s advice, whether he recommends chemo only or chemo + surgery. My best wishes to your family

OC_DriftExample_P16

My friend has a relapsed ovarian cancer (spread to lungs and stomach) and was able to stop the cancer with dandelion root and leaves (ca 124 was stopped increasing and the water in the lungs disappeared) before she started a new series of chemo (6 times). In the nordic countries we must wait a few weeks before a chemo can be started so the ca 124 was measured 2 times before the therapy started. Now the lung metastasis is gone and she only has a few enlarged lymph nodes in the stomach area. The doctors are amazed about her recovery because her cancer is of an aggressive type. She will now do the following:

1. continue eating dandelion

2. take food soda to keep her body alcalic, the cancer cannot use the nutrition from surrounding healthy tissue as long as it is alkalic, the cancer melts surrounding tissue with acidic enzymes and the alcality neutralizes the acides.

3. eat lysine and alcalic vitamine c (calcium ascorbat). The use of lysine (3–8 grams/day) blocks arginine. Arginine cannot be produced by the cancer cells but it is necessary for the dividing of the cells (multiplying of the DNA). Without arginine the cancer cannot divide and spread.

Has anybody tried this or any other successful method to survive?

REFERENCES

ACS, (2017a). American Cancer Society. Cancer Survivors Network. Retrieved on Aprill, 20, 2017, from https://csn.cancer.org/forum.

ACS, (2017b). American Cancer Society. What Are the Key Statistics About Ovarian Cancer? Retrieved on April, 20, 2017, from www.cancer.org/cancer/ovarian-cancer/about/key-statistics.html.

ACS, (2017c). American Cancer Society. What is Prostate Cancer? Retrieved on April 20, 2017, from www.cancer.org/cancer/prostate-cancer/about/what-is-prostate-cancer.html.

ACS, (2017d). American Cancer Society. Key Statistics for Prostate Cancer. Retrieved on April 20, 2017, from www.cancer.org/cancer/prostate-cancer/about/key-statistics.html.

Alexander, S. C., Peterson, J. L. & Hollingshead, A. B. (2003). *Help is at your keyboard: Support groups on the Internet.* In L. R. Frey (Eds.), *Group Communication in Context. Studies of Bona Fide Groups* (pp. 309-334). Mahwah, NJ: Lawrence Erlbaum Associates Publishers.

Anderson, S. J., Dewshirst, T. & Ling, P. M. (2006). Every document and picture tells a story: using internal corporate document reviews, semiotics, and content analysis to assess tobacco advertising. *Tobacco Control*, ***15***, 254-261.

Andreassen, H. K. Bujnowska-Fedak, M. M. Chronaki, C. E. Dumitru, R. C. Pudule, I. Santana, S., . . . Wynn, R. (2007). European Citizen Use of E-health Services: A study of Seven Countries. *BMC Public Health*, ***7***(53), 67-84.

Ankem, K. (2006). Factors influencing information needs among cancer patients: A meta-analysis. *Library and Information Science Research*, ***28***, 7-23.

Ankem, K. (2007). Information-seeking behavior of women in their path to an innovative alternate treatment for symptomatic uterine fibroids. *Journal of the Medical Library Association*, ***95***(2), 164-172.

ASRM, (2017). American Society for Reproductive Medicine. ReproductiveFacts.org. Retrieved on April 20, 2017, from http://www.reproductivefacts.org/faqs/frequently-asked-questions-about-infertility/.

Atkinson, N. L., Saperstein, S. L. & Pleis, J. (2009). Using the Internet for health-related activities: Finding from a national probability sample. *Journal of Medical Internet Research*, ***11***(1).

Attrill, A. (2015). *Cyberpsychology*. Oxford, UK: Oxford Univ Press.

Baker, D. (2006). The meaning and measure of health literacy. *Journal of General Internal Medicine*, ***21***(8), 878-883.

Baker, L. (2005). *Monitoring and Blunting.* In K. E. Fisher, S. Erdelez & L. Mckechnie (Eds.), *Theories of Information Behavior* (pp. 239-241). Medford, NJ: Information Today, Inc.

Baker, L. M. & Pettigrew, K. E. (1999). Theories for Practitioners: two frameworks for studying consumer health information-seeking behavior. *Bulletin of Medical Library Association*, ***87***(4), 444-450.

Bales, R. F. (1951). *Interaction process analysis: A method for the study of small groups.* Cambridge, MA: Addison-Wesley Press.

Ballantine, P. W. & Stephenson, R. J. (2011). Help me, I'm fat! Social Support in online weight loss networks. *Journal of Consumer Behavior*, ***10***(6), 332-337.

Bansal, G., Zahedi, F. & Gefen, D. (2010). The impact of personal disposition on information sensitivity, privacy concern and trust in disclosing health information online. *Decision Support Systems*, ***49***, 138-150.

Bansil, P., Keenan, N. L. & Gilliland, J. C. (2006). Health-related information on the Web: results from the HealthStyles Survey 2002-2003. *Journal of Preventive Chronic Diseases*, ***3***(2).

Barak, A., Boniel-Nissim, M. & Suler, J. (2008). Fostering empowerment in online support groups. *Computers in Human Behavior*, ***24***, 1867-1883.

Barlett, J. 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***(1), 113-119.

Bartlett, J. C. & Toms, E. G. (2005). "How is Information used? Applying task analysis to understanding information use." In Proceedings of the Canadian association for information science, CAIS. London,ON, pp.

Bartlett, J. C. & Toms, E. G. (2013). "How is Information used? Applying task analysis to understanding information use." In Proceedings of the Annual Conference of CAIS/Actes du congrÃ¨s annuel de l'ACSI. pp.

Bates B, Romina S, Ahmed R & D, H. (2006). The effect of source credibility on consumers' perceptions of the quality of health information on the Internet. *Med Inform Internet Med*, ***31***(1), 45-52.

Bauerle Bass, S. (2003). How Will Internet Use Affect the Patient? A Review of Computer Network & Closed Internet-based System. Implications in Understanding How the Use of the Internet Affects Patient Populations. *Journal of Health Psychology*, ***8***(1), 25-38.

Bauerle Bass, S., Ruzek, S. B., Gordon, T. F., Fleisher, L., McKeown-Conn, N. & Moore, D. (2006). Relationship of Internet Health Information Use With Patient Behavior and Self-Efficacy: Experiences of Newly Diagnosed Cancer Patients Who Contact the National Cancer Institute's Cancer Information Service. *Journal of Health Communications*, ***11***, 219-236.

Bedsworth, J. A. & Molen, M. T. (1982). Psychological stress in spouses of patients with myocardial infarction. *Heart & Lung*, ***11***(5), 450-456.

Bender, J. L., Jimenez-Marroquin, M.-C. & Jadad, A. R. (2011). Seeking Support on Facebook: A Content Analysis of Breast Cancer Groups. *Journal of Medical Internet Research*, ***13***(1).

Berland, G. K., Elliot, M. N., Morales, L. S., Algarzy, J. I., Kravitz, R. L. & Broder, M. S. (2001). Health Information on the Internet: accessibility, quality, and readability in English and Spanish. *Journal of the American Medical Association*, ***285***(20), 2612-2621.

Beyer, J. & Trice, H. (1982). The utilization process: a conceptual framework and synthesis of empirical findings. *Administrative Science Quaterly*, ***27***(4), 591-622.

Bickart, B. & Schindler, R. M. (2001). Internet Forum as Influential Sources of Consumer Information. *Journal of Interactive Marketing*, ***15***(3), 31-40.

Biyani, P., Caragea, C., Mitra, P. & Yen, J. (2014). "Identifying Emotional and Informational Support In Online Health Communities." In The 25th International Conference on Computational Linguistics (COLING 2014) Dublin, Ireland, pp.

Blank, T. O. & Adams-Blodnieks, M. (2007). The Who and the What of usage of two Cancer Online Communities. *Computers in Human Behavior*, ***article in press***.

Blank, T. O., Schmidt, S. D., Vangsness, S. A., Monteiro, A. K. & Santaga, P. V. (2010). Differences among breast and prostate cance online support groups. *Computer in Human Behavior*, ***26***, 1400-1404.

Bond, M. (2000). Information use: appreciating the subtleties. *British Journal of Therapy and Rehabilitation*, ***7***(5), 241-245.

Booske, B. C. & Sainfort, F. (1998). Relation between Quantitative and Qualitative Measures of Information Use. *International Journal of Human-Computer Interaction.*, ***10***(1), 1-21.

Boukes, M., Boomgaarden, H. G., Moorman, M. & De Veese, C. H. (2015). Political news with a personal touch: how human interest framing indirectly affects policy attitudes. *Jouranl of Mass Communication Quarterly*, ***92***, 121-141.

Bradley, J. (1993). Methodological Issues and Practices in Qualitative Research. *Library Quarterly*, ***63***(4), 431-449.

Brookes, B. (1975). In (Eds.), (pp.

Brown, M. (1991). "A General Model of Information-Seeking Behavior." In Proceedings of the 54th Annual Meeting of the American Society for Information Science. pp. 9-14. Medford, NJ: Learned Information.

Bruce, C. & Hughes, H. (2010). Informed Learning: A pedagogical construct attending simultaneously to information use and learning. *Library and Information Science Research*, ***32***(4), A2-A8.

Buckland, S. (1994). Unmet needs for Health Information: A Literature Review. *Health Libraries Review*, ***11***, 82-95.

Burnett, G. (2000). Information Exchange in Virtual Communities: a typology. *Information Research*, ***5***(4).

Caine, K. E., Burnham, K. E., Fisk, A. D. & Rogers, W. A. (2008). Privacy Concerns and Disclosure Behavior in a Health Setting. *Proceedings of the Human Factors and Ergonomics Society Annual meeting*, ***52***(22), 1785–1789.

Calabretta, N. (2002). Consumer-driven Patient-centered Health Care in the Age of Electronic Information. *Journal of Medical Library Association*, ***90***(1), 32-37.

Case, D. O. (2007). *Looking for Information. A Survey of Research on Information Seeking, Needs, and Behavior.* London, UK: Elsevier.

Case, D. O. (2012). *Looking for information: A survey of research on information seeking, needs and behavior*: Emeral Group Publishing Limited.

Case, D. O. (2014). "Sixty years of measuring the use of information and its sources: from consultation to application." In Libraries in the Digital Age (LIDA) Proceedings. pp. 13-20.

CDC, (2017). Center for Disease Control and Prevention. Infertility FAQs. Retrieved on April 20, 2017, from www.cdc.gov/reproductivehealth/Infertility/index.htm). .

Chatterjee, P. (2001). Online Reviews – Do Consumers Use Them? *Advances in Consumer Research*, ***28***, 129-133.

Chen, A. (2014). Information Use and Illness Representations: Understanding Their Connection in Illness Coping. *Journal of the Association for Information Science and Technology.*

Chen, A. T. (2012). Exploring online support spaces: Using cluster analysis to examine breast cancer, diabetes and fibromyalgia support groups. *Patient Education and Counseling,* ***87***(2), 250-257.

Chen, F.-C., Lee, Y.-W., Chu, H. C., Wang, H. R. & Jian, H.-M. (2005). "Effective Discussions, Social Talks and Learning: A Paradox on Learning in Discussion Forums." In Proceedings of the 2005 Conference on Computer Support for Collaborative Learning: learning 2005: the next 10 years! , pp. 33-42.

Cheong-Iao Pang, P., Verspoor, K., Chang, S. & Pearce, J. (2015). Conceptualising health information seeking behaviors and exploratory search: result of a qualitative study*. Health Technology.*

Choo, C. W. (2002). *Information Management for the Intelligent Organization: The Art of Scanning the Enviroment.* Medford, New Jersey: Information Today, Inc.

Chung, J. E. (2013). Social Interaction in online support groups: preference for online social interaction over offline social interaction. *Computers in Human Behavior*, ***29***(4), 1408-1414.

Chung, J. E. (2014). Social Networking in Online Support Goups for Health: How online Social Networking Benefits Patients. *Journal of Health Communications*, ***19***, 639-659.

Cline, R. J. & Haynes, K. M. (2001). Consumer Health Information Seeking on the Internet: the state of the art. *Health Education Research*, ***16***(6), 671-692.

Coiera, E. (1996). The Internet's challenge to health care provision. *British Medical Journal*, ***312***(7022), 3-4.

Cole, J., Watkins, C. & Kleine, D. (2016). Health Advise from Internet Discussion Forums: How Bad Is Dangerous? *Journal of Medical Internet Research*, ***18***(1).

Colineau, N. & Paris, C. (2010). Talking about your health to strangers: understanding the use of online social networks by patients. *New Review of Hypermedia and Multimedia*, ***16***(1-2), 141-160.

Coreil, J. & Behal, R. (1999). Man to Man prostate cancer support groups. *Cancer Practice*, ***7***(3), 122-129.

Costigan, J. (1999). *Introduction: forests, trees, and Internet research.* In S. Jones (Eds.), *Doing Internet research: Critical issues and methods for examining the net* (pp. XVII-XXIV). London: Sage Publication, Inc.

Cotten, S. R. & Gupta, S. S. (2004). Characteristics of online and offline health information seekers and factors that discriminate between them. *Social Science and Medicine*, ***59***, 1795-1806.

Coulson, N. S. (2005). Receiving Social Support Online: An Analysis of a Computer-Mediated Support Group for Individuals Living with Irritable Bowel Syndrome. *CyberPsychology & Behavior*, ***8***(6), 580-584.

Coulson, N. S., Buchanan, H. & Aubeeluck, I. (2007). Social support in Cyberspace: A content analysis of communication within a Huntington's disease online support group. *Patient Education and Counseling*, ***68***, 173-178.

Crangle, C., E & Kart, J. B. (2015). A questions-based investigation of consumer mental-health information. *PeerJ*, ***3***.

Crocco, A. G., Villasis-Keever, M. & Jadad, A. R. (2002). Analysis of Cases of Harm Associated With Use of Health Information on the Internet. *Journal of the American Medical Association*, ***287***(21), 2869-2871.

Culver, J. D., Gerr, F. & Frumkin, H. (1997). Medical Information on the Internet: A study of an electronic bulletin board. *Journal of General Internal Medicine*, ***12***(8), 466-471.

CyberDialogue (2000) *Cyber Dialogue Releases Cybercitizen Health 2000*. from http://cyberdialogue.com/news/release/2000/08-22-cch-launch.html

D'Alessandro, D. M., D'Alessandro, M. P. & Colbert, S. I. (2000). A Proposed Solution for Addressing the Challenge of Patient Cries for Help Through an Analysis of Unsolicited Electronic Email. *Pediatrics*, ***105***(6), 74-80.

Darley, W. K., Blankson, C. & Luethge, D. J. (2010). Toward an integrated framework for consumer behavior and decision making process: a review. *Psychology & Marketing*, ***27***, 94-116.

Davison, K., Pennebaker, J. W. & Dickerson, S. S. (2000). Who Talks? The Phychology of Illness Support Groups. *American Phychologist*, ***55***(2), 205-217.

De Choudhury, M., Morris, M. R. & White, R. W. (2014). "Seeking and sharing health information online: comparing search engines and social media." In Proceedings of the 32nd annual ACM conference on Human factors in computing systems. pp. 1365-1376. ACM.

Dean, K. (1986). Lay Care in Illness. *Social Science and Medicine*, ***22***(2), 275-284.

Dervin, B. (1976). *The Everyday Information Needs of the Average Citizen. A Taxonomy for Analysis*. In M. Kochen & J. C. Donohue (Eds.), *Information for the Community* (pp. 19-38). Chicago: American Library Association.

Dervin, B., Harlock, S., Atwood, R. & Garzona, C. (1980). *The Human Side of Information: An Exploration in a Health Communication Context*. In M. Burgoon (Eds.), *Communication Yearbook* (pp. 591-608).

Dervin, B., Jacobson, T. & Nilan, M. (1982). *When Cancer Strikes: How cancer patients make sense of their health situations*. Report to the Office of Cancer Communications, National Cancer Institute, Procurement order #263-MD-102094-3.

Dervin, B., Nilan, M. & Jacobson, T. (1982b). *Improving predictions of Information Use: A comparison of predictor types in a Health Communication* *setting*. In (Eds.), *Communication Yearbook 5* (pp. 807-830). New Brunswick and London: The International Communication Association.

Dervin, B. (1983a). *Information as a user construct: The relevant of perceived information needs to synthesis and interpretation.* In S. A. Ward & L. J. Reed (Eds.), *Knowledge Structure and Use: Implications for Synthesis and Interpretation* (pp. Philadelphia, PA: University Press.

Dervin, B. (1983b). An overview of Sense-Making research: Concepts, Methods, and results to date. Paper presented at the annual meeting of the International Communication Association. Dallas, TX, Available: http://communication.sbs.ohio-state.edu/sense-making/art/artdervin83.html

Dervin, B., Harlock, S., Atwood, R. & Garzona, C. (1986). *The Human Side of Information: An Exploration in a Health Communication Context*. In (Eds.), *Communication Yearbook* (pp. 591-608).

Dervin, B. & Nilan, M. (1986). Information Needs and Uses*. Annual Review of Information Science and Technology*, ***21***, 3-33.

Dervin, B. (1992). *From the Mind's Eyes of the User: The sense-making Qualitative-Quantitative Methodology.* In (Eds.), *Qualitative Research in Information Management. J. D. Glazier and R. R. Powell (eds)* (pp. 61-84.). Englewood, CO: Libraries Unlimited.

Dervin, B. (2003). Human studies and user studies: a call for methodological inter-disciplinarity. *Information Research*, ***9***(1).

Detlefsen, E. G. (1998). The Information Behaviors of Life and Health Scientists and Health Care Providers: characteristics of the research literature. *Bulletin of Medical Library Association*, ***86***(3), 385-390.

Edelmann, N. (2013). Reviewing the Definitions of "Lurkers" and some Implications for Online Research. *Cyberpsychology, Behavior, and Social Networking*, ***9***, 645-649.

Entman, R. M., Matthes, J. & Pellicano, L. (2009). *Nature, sources and effects of news framing.* In (Eds.), *The handbook of journal studies* (pp. 175-190). New York, NY: Routledge.

Entwistle, V. A., France, E. F., Wyke, S., Jepson, R., Hunt, K., Ziebland, S. & Thompson, A. (2011). How information about other people's personal experiences can help with healthcare decision-making: A qualitative study. *Patient Education and Counseling*, ***85***.

Epstein, Y. M., Rosenberg, H. S., Venet Grant, T. & Hemenway, N. (2002). Use of the Internet as the only outlet for talking about Infertility. *Fertility and Sterility*, ***78***(3), 507-514.

Erdelez, S. (1995). *Information Encountering. An exploration beyond information seeking.* (Doctoral Thesis). Syracuse University, Syracuse, NY.

Evans, S. H. & Clarke, P. (1983). *When Cancer patients fail to get well: flaws in health communication.* In (Eds.), *Communication Yearbook 7* (pp. 225-248). New Brunswick, NJ: Transaction.

Evers, K. E., Prochaska, J. O., Driskell, M. M., Cummins, C. O. & Velicer, W. F. (2003). Strengths and Weaknesses of Health Behavior Change Programs on the Internet. *Journal of Health Psychology*, ***8***(1), 63-70.

Eysenbach, G. & Diepgen, T. L. (1999). Shopping around the Internet today and tomorrow: towards the millennium of cybermedicine. *British Medical Journal*, ***319***, 1294.

Eysenbach, G. (2001). What is e-health? *Journal of Medical Internet Research*, ***3***(2).

Eysenbach, G. (2002). Empirical Studies Assessing the Quality of Health Information for Consumers on the World Wide Web. A Systematic Review. *British Medical Journal*, ***287***(20), 2691-2700.

Eysenbach, G. & Kohler, C. (2002). How do comsumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *BMJ* ***324***(7337), 573-577.

Eysenbach, G. (2003). The Impact of the Internet on Cancer Outcomes. *CA A Cancer Journal for Clinicians*, ***53***(6), 356-371.

Fan, Y.-W., Wu, C.-C. & Chiang, L.-C. (2009). "Knowledge sharing in virtual community: The comparison between contributors and lurkers." In The 9th International Conference on electronic business. Macau, pp. 662-668.

Fernsler, J. I. & Manchester, L. J. (1997). Evaluation of a Computer-Based Cancer Support Network. *Cancer Practice*, ***5***(1), 46-51.

FertileThoughts, (2017). Forum. Retrieved on April, 20, 2017, from http://www.fertilethoughts.com/forums/.

Fiksdal, A. S., Kumbamu, A., Jadhav, A. S., Cocos, C., Nelsen, L. A., Pathak, J. & McCormick, J. B. (2014). Evaluating the Process of Online Health Information Searching: A Qualitative Approach to Exploring Consumer Perspectives. *Journal of Medical Internet Research*, ***16***(9).

Fleisher, L., Bauerle Bass, S., Burt Ruzek, S. & McKeown-Conn, N. (2002). "Relationship among Internet health information use, patient behavior and self-efficacy in newly diagnosed cancer patients who contact the National Cancer Institute's (NCI) Atlantic Region Cancer Information Service (CIS)." In Proceedings of the AMIA 2002 Annual Symposium. pp. AMIA.

Folger, J. P., Hewes, D. E. & Poole, M. S. (1984). *Coding Social Interaction.* In B. Dervin & M. Voight (Eds.), *Progress in Communication Sciences* (pp.

Folkman, S. & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, ***21***, 219-239.

Forkner-Dunn, J. (2003). Internet-based Patient Self-care: The Next Generation of Health Care Delivery. *Journal of Medical Internet Research*, ***5***(2), e8.

Fossey, E., Harvey, C., McDermott, F. & Davidson, L. (2002). Understading and evaluting qualitative research. *Australian and New Zeeland Journal of Psychiatry*, ***36***, 717-732.

Fox, S. & Rainee, L. (November 26, 2000). *The Online Health Care Revolution: How the Web Helps Americans to take better care of themselves*. Pew Internet American Life Project,

Fox, S. & Fallows, D. (July 16, 2003). *Internet Health Resources*. Pew Internet American Life Project,

Fox, S. (May 17, 2005). *Health Information Online*. Pew Internet & American Life Project,

Fox, S. (February 28, 2011). *Peer-to-peer Health Care*. Pew Internet American Life Project,

Fox, S. (Feb, 20, 2013). *Pew Internet: Health.*

Fox, S. & Duggan, M. (January 15, 2013). *Health Online 2013*. Pew Internet & American Life Project,

Fox;, S. & Purcell, K. (March 24, 2010). *Chronic Disease and The Internet*. Pew Internet & American Life Project, The Pew Research Center,

Frankfort-Nachmias, C. & Nachmias, D. (1996). *Research Methods in the Social Sciences*. New York: NY: St. Martin's Press, Inc.

Frost, J., Vermeulen, I. E. & Beekers, N. (2014). Anonymity Versus Privacy: Selective Information Sharing in Online Cancer Communities. *Journal of Medical Internet Research*, ***16***(5).

Frost, J. H. & Massagli, M. P. (2008). Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data. *Journal of Medical Internet Research*, ***10***(3).

Galdas, P. M., Cheater, F. & Marshall, P. (2005). Men and health-seeking behavior: literature review. *Journal of Advanced Nursing*, ***49***, 616-623.

Gann, R. (1991). Consumer Health information: The Growth of an Information Specialism. *Journal of Documentation*, ***47***(3), 284-308.

Gantz, W., Fitzmaurice, M. & Fink, E. (1991). Assessing the active component of information seeking. *Journalism Quaterly*, ***68***(4), 630-637.

George, D. R., Rovniak, L. S. & Kraschnewski, J. L. (2013). Dangers and opportunities for social media in medicine. *Clinical obstetrics and gynecology*, ***53***(3).

Ginossar, T. (2011). *"There's Always Hope:" Content, Participants, and Dynamics of Discussion in a Lung Cancer Internet Support Group.* In L. Shedletsky & J. E. Aitken (Eds.), *Cases on Online Discussion and Interaction: Experiences and Outcomes* (pp. 302-318). Hershey, PA: IGI Global.

Goldsmsith, D. J. & Albrecht, T. L. (2011). *Social support, social networks, and health.* In T. L. Thompson, R. Parrott & J. F. Nussbaum (Eds.), *The Routledge handbook of health communication* (pp. 335-348). New York: Routledge.

Gooden, R. J. & Winefield, H. R. (2007). Breast and Prostate Cancer Online Discussion Boards*. Journal of Health Psychology,* ***12***(1), 103-114.

Graesser, A. C., Person, N. & Huber, J. (1992). *Mechanisms that generate questions.* Hillsdale, NJ, US: Lawrence Erlbaum Associates.

Graesser, A. C., McHahen, C. L. & Johnson, B. K. (1994). *Question asking and answering* In M. A. Gerbnsbacher (Eds.), *Handbook of phycholinguistics* (pp. San Diego: Academic Press.

Granovetter, M. (1982). *The Strength of Weak Ties: A Network Theory Revisited.* In P. Marsden; & N. Lin (Eds.), *Social Structure and Network Analysis* (pp. New York: John Wiley and Sons.

Gray, J. H. & Densten, I. L. (1998). Integrating quantitative and qualitative analysis using latent and manifest variables. *Quality and Quantity*, ***32***, 419-431.

Gray, R. E., Fitch, M., Davis, C. & Phillips, C. (1997). Interview with men with prostate cancer about their self-help group experience. *Journal of Palliative Care*, ***13***(1), 15-21.

Grimes, A., Landry, B. M. & Grinter, R. E. (2010). "Characteristics of Shared Health Reflections in a Local Community." In CSCW'10 Computer Supported Cooperative Work Savannah, Georgia, USA, pp. 435-444. ACM.

Grimsbo, G. H., Engelsrud, G. H., Ruland, C. M. & Finset, A. (2012). Cancer Patients' experiences of using an Interactive Health Communication Application (IHCA). *Int J Qualitative Stud Heatlh and Well-being*, ***7***(15511), 1-14.

Gualtieri, L. N. (2009). The Doctor as the Second Opinion and the Internet as the First. CHI 2009. Boston, MA, USA
ACM.

Gustafson, D. H. Wise, M. McTavish, F. M. Taylor, J. O. Wolberg, W. Stewart, J., . . . Bosworth, K. (1993). Development and pilot evaluation of a computer-based support system for women with breast cancer. *Journal of Psychosocial Oncology*, ***11***(4), 69-93.

Gustafson, D. H., Robinson, T. N., Ansley, D., Adler, L. & Brennan, P. F. (1999). Consumers and Evaluation of Interactive Health Communication Applications. *Journal of Preventive Medicine*, ***16***(1), 23–29.

Hajli, M. N. (2014). A study of the impact of social media on consumers. *International Journal of Market and Research*, ***56***(3), 387-404.

Hall, H. J. (1981). Patterns in the Use of Information: The Right to be Different. *Journal of the American Society for Information Science.*, ***32***, 103-112.

Hallyburton, A. & Evans, L. A. (2014). Gender and online health information seeking: A five study meta-analysis of web content. *Journal of Consumer Health on the Internet*, ***18***(2), 128-142.

Han, H.-R. & Belcher, A. E. (2001). Computer-Mediated Support Group Use Among Parents of Children with Cancer--An exploratory study. *Computers in Nursing*, ***19***(1), 27-33.

Harrison, J., Maguire, P. & Pitceathly, C. (1995). Confiding in crisis: Gender differences in pattern of confinding among cancer patients. *Social Science and Medicine*, ***41***(9), 1255-1260.

Henri, F. (1992). *Computer Conferencing and Content Analysis*. In A. R. Kaye (Eds.), *Collaborative learning through computer conferencing* (pp. 117-136). Berlin: Springer-Verlag.

Herring, S. C. (2004). *Computer-Mediated Discourse Analysis: An approach to Researching Online Behavior*. In S. Barab;, R. Kling; & J. H. Gray (Eds.), *Designing for Virtual Communities in the Service of Learning* (pp. 338-376). New York: Cambridge University Press.

Hert, P. (1997). Social dynamics of an on-line scholarly debate. *The Information Society*, ***13***, 329-360.

HHS (2014). Using Health Text Messages to Improve Consumer Health Knowledge, Behaviors, and Outcomes. An Environmental Scan. . D. o. H. a. H. Services, Health Resources and Services Administration.

Higgins, O., Sixsmith, J., Barry, M. M. & Domegan, C. (October, 2011). *A literature review on health information seeking behaviour on the web: a health consumer and health professional perspective.* Insights into health communication

Hill, K. A. & Hughes, J. E. (1997). Computer-Mediated Political Communication: The USENET and Political Communities. *Political Communication*, ***14***, 3-27.

Hong, Y., Peña-Purcell, N. & Ory, M. G. (2012). Outcomes of online support resources for cancer survivior: A systematic literature review. *Patient Education and Counseling*, ***86***, 288-296.

Howison, J., Crowston, K. & A., W. (2011). Validity issues in the use of social network analysis with digital trace data. *Journal of the Association for Information Systems*, ***12***(12).

Hsieh, H.-F. & Shannon, S. E. (2005). Three approaches to Qualitative Content Analysis. *Qualitative Health Research*, ***15***(9), 1277-1288.

Hu, X., Bell, R. A., Kravitz, R. L. & Orrange, S. (2012). The Prepared Patient: Information Seeking of Online Support Group Members Before Their Medical Appointments. *Journal of Health Communications*, ***17***, 960-978.

Hu, Y. & Sundar, S. S. (2010). Effects of online health sources on credibility and behavioral intentions,. *Communication Research*, ***37***, 105-132.

Huang, H. Y. (2016). Examining the beneficial effects of individual's self-disclosure on the social network site. *Computers in Human Behavior*, ***57***, 122-132.

Hummel, F. I. (2016). *Powerlessness*. In P. D. Larsen (Eds.), *Lbkin's Chronic Illness. Impact and Intervention* (pp. 261-288): Jones & Bartlett Learning, LLC.

Humphrey, T. (Sep 15, 2011). *The Growing Influence and Use Of Health Care Information Obtained Online*. The Harris Poll, Hymovich, D. P. & Hagopian, G. A. (1992). *Chronic illness in childrens and adults: A psychosocial approach*. Philadelphia.

Jacob, E. (2012). *The Intelligent Patient Overview*. In E. Jacob (Eds.), *Medifocus Guidebook on Female Infertility*. (pp. 19-44). Silver Spring, MD: Medifocus.com,Inc.

Jansen, B. J., Taksa, I. & Spink, A. (2009). *Research and Methodological Foundations of Transaction Log Analysis* In I. Global (Eds.), *Handbook of Research on Web Log Analysis* (pp. 1-16).

Jayanthi, A. (2015) *Consumers vs. patients: Healthcare's biggest misunderstanding*. Becker's Health IT & CIO Review. Health Information Technology from

Johnson, G. J. & Ambrose, P., J. (2006). Neo-Tribes: The Power and Potential of Online Communities in Health Care. *Communications of the ACM*, ***49***(1), 107-113.

Johnson, J. D. & Meischke, H. (1991). Women's preferences for cancer information from specific communication channels. *American Behavioral Scientist*, ***34***, 742-755.

Johnson, J. D. & Meischke, H. (1993). A comprehensive model of cancer related information seeking applied to magazines. *Human Communications Research*, ***19***, 343-367.

Johnson, R. B. (1997). Examining the validity structure of qualitative research. *Education*, ***118***, 282-292.

Jones, Q. (1997). Virtual-Communities, Virtual Settlements & Cyber-Archeology: A Theoretical Outline. *Journal of Computer Mediated Communication*, ***3***(3).

Kam, L. E. & Chismar, W. G. (2002). A Self-disclosure Model for Personal Health Information. *Proceedings of the 36th Hawaii International Conference on System Sciences.*

Kammerer, Y., Braten, I., Gerjets, P. & Stromso, H. I. (2013). The role of Internet-specific epidtemic beliefs in laypersons' source evaluations and decisions during Web search on a medical issue. *Computers in Human Behavior*, ***29***, 1193-1203.

Kari, J. (2010). Diversity in the conceptions of information use*. Information Research*, ***15***(3).

Katz, A. (2012). *One of the Guys: Joining a Support Group*. In (Eds.), *Prostate Cancer and the Man you Love: Supporting and Caring for your Partner* (pp. 149-158): Rowman & Littlefield Publishers.

Katzer, J. (1987). User Studies, Information Science, and Communication. *The Canadian Journal of Information Science*, ***12***(3), 15-30.

Katzer, J., Cook, K. H. & Crouch, W. W. (1998). *Evaluating Information. A guide for users of Social Science Research.* Boston: McGraw-Hill.

Kaye, A. R. (1992). *Learning Together Apart.* In A. R. Kaye (Eds.), *Collaborative Learning Through Computer Conferencing* (pp. 1-24): Springer Berlin Heidelberg.

Kaye, B. & Johnson, T. (1999). Research Methodology: Taming the Cyber Frontier. *Social Science Computer Review*, ***17***, 323-337.

Kelly, L., Jenkinson, C. & Ziebland, S. (2013). Measuring the effects of online health information for patients: Item generation for an e-health impact questionnaire. *Patient Education and Counseling*, ***93***(3), 433-438.

Khoo, C. S. G. (2014). Issues in Information Behavior on Social Media. *Libres. Library and Information Science e-Journal*, ***24***(2), 75-96.

Kienhues, D. & Bromme, R. (2012). Exploring laypleople's epistemic belief about medicine - a factor-analitic survey study. *BCM Public Health*, ***12***(759).

King, S. A. & Moreggi, D. (1998). *Internet therapy and self-help groups--the pros and the cons.* In J. Gackenbach (Eds.), *Psychology and the Internet: Intrapersonal, Interpersonal, and Transpersonal Implications.* (pp. 77-109). San Diego, CA: Academic Press.

Kitzmann, J. H., Hermkens, K., McCarthy, I. P. & Silvestre, B. S. (2011). Social Media? Get Serious! Understanding the functional building blocks of social media. *Business Horizons*, ***54***(3), 241-251.

Klemm, P., Reppert, K. & Visich, L. (1998). A Nontraditional Cancer Support Group. The Internet. *Computers in Nursing*, ***16***(1), 31-36.

Klemm, P., Hurst, M., Dearholt, S. L. & Trone, S. R. (1999). Cyber Solace. Gender Differences on Internet Cancer Support Groups. *Computers in Nursing*, ***17***(2), 65-72.

Klemm, P. & Hardie, T. (2002). Depression in Internet and face-to-face cancer support groups: a pilot study. *Oncology Nursing Forum.*, ***29***(4), E45-51.

Klemm, P., Bunnell, D., Cullen, M., Soneji, R., Gibbons, P. & Holecek, A. (2003). Online Cancer Support Groups. A review of Research Literature. *CIN: Computers, Informatics, Nursing*, ***21***(3), 136-142.

Kollock, P. & Smith, M. A. (1999). *Communities in Cyberspace*. In P. Kollock & M. A. Smith (Eds.), *Communities in Cyberspace* (pp. 2-25). London and New York: Routledge.

Kontos, E., Blake, K. D., Chou, W. Y. & Prestin, A. (2014). Predictors of eHealth Usage: Insights on The Digital Divide From the Health Information National Trends Survey 2012. *Journal of Medical Internet Research*, ***16***(7).

Kral, G. (2006). *Online communities for mutual help: Fears, fiction, and facts*. In M. Murero & R. E. Rice (Eds.), *The Internet and Health care: Theory, research, and practice* (pp. 215-232). Mahwah, NJ: Lawrence Erlbaum.

Krikelas, J. (1983). Information-Seeking Behavior: Patterns and Concepts. *Drexel Library Quarterly*, ***19***(6), 5-20.

Krippendorff, K. (1980). *Content Analysis. An Introduction to Its Methodology.* Newbury Park: CA: Sage Publications.

Kuhlthau, C. (1991). Inside the Search Process: Information Seeking from the User's Perspective. *Journal of the American Society for Information Science and Technology*, ***42***(5), 361-371.

Kuhlthau, C. (1993). A principle of uncertainty for information seeking. *Journal of Documentation*, ***49***(4), 339-355.

Kuhlthau, C. (2004). *Seeking Meaning. A Process Approach to Library and Information Services.* Wesport, Connecticut: Libraries Unlimited.

Lane, J. M. & Addis, M. E. (2005). Male gender role conflict amd patterns of help seeking in Costa Rica and the United States. *Phychology of Men & Masculinity*, ***6***(3), 155-168.

Larkin, M. (2000, May 20, 2000). "Online Support Groups Gaining Credibility." *The Lancet*, 355 (9217), pp. 1834

Lee, F. & Peterson, C. (1997). Content Analysis of Archival Data. *Journal of Consulting and Clinical Psychology*, ***65***, 959-969.

Lee, K., Hoti, K., Hughes, J. D. & Emmerton, L. (2014a) *Interventions to assist health consumers to find reliable online health information: a comprehensive review*. PluS ONE **9** (4) Retrieved from http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0094186

Lee, K., Hoti, K., Hughes, J. D. & Emmerton, L. (2014b). Dr Google and the Consumer: A Qualitative Study Exploring the Navigational Needs and Online Health Information-Seeking Behaviors of Consumers With Chronic Health Conditions. *Journal of Medical Internet Research*, ***16***(12).

Lee, S. Y., Hwang, H., Hawkins, R. & Pingree, S. (2008). Interplay of negative emotion and health self-efficacy on the use of health information and its outcomes. *Communication Research*, ***35***, 358-381.

Lee, S. Y. & Hawkins, R. (2010). Why do Patients Seek an Alternative Channel? The Effects of Unmet Needs on Patients'Health-Related Internet Use. *Journal of Health Communications*, ***15***, 152-166.

Legris, P., Inghamb, J. & Collerettec, P. (2003). Why do people use information technology? A critical review of the technology acceptance model. *Information & Management*, ***40***(3), 191–204.

Leimeister, J. M. & Kremar, H. (2005). Evaluation of a Systematic Design for a Virtual Patient Community. *Journal of Computer-Meadiated Communication*, ***10***(4).

Levitt, M., Lamb, S. & Voss, B. (1996). Brain tumor support group: Content themes and mechanisms of support. *Oncology Nursing Forum.*, ***23***(8), 1247-1256.

Lewis, D. (1998). The Internet as a source for Healtcare Information. *Diabetes Education*, ***24***, 627-630.

Leydon, G. M., Boulton, M., Moynihan, C., Jones, A. & Mossman, J. (2000). Cancer patients' information needs and information seeking behavior: in depth interview study. *British Medical Journal*, ***320***, 909-913.

Li, N., Orrange, S., Kravitz, R. L. & Bell, R. A. (2014). Reasons for and predictors of patients' online health information seeking following a medical appointment. *Family Practice*, ***31***(5), 550-556.

Li, S., Feng, B., Li, N. & Tan, X. (2015). How social context cues in online support-seeking influence self-disclosure in support provision. *Communication Quarterly*, ***63***(5), 586-602.

Lincoln, Y. & Guba, E. (1985). *Naturalistic Inquiry*. Beverly Hills: CA: Sage Publications.

Longo, D. R., Patrick, T. B. & Kruse, R. (2001). The natural history of the use of health care information by women with breast cancer: a conceptual model. *American Medical Informatic Association*, 413-417.

Lustria ML, Smith SA & CC, H. (2011). Exploring digital divides: an examination of eHealth technology use in health information seeking, communication and personal health information management in the USA. *Health Informatics Journal*, ***17***(3), 224-243. .

Macias, W., Stavchansky, L. & Smith, T. (2005). Health-Related Message Boards/Chat Rooms on the Web: Discussion Content and Implications for Pharmaceutical Sponsorships. *Journal of Health Communications*, ***10***, 209-223.

Mackenzie, C. S., Gekoski, W. I. & Knox, V. J. (2006). Age, gender, and the underutilization of mental health services: the influence of help-seeking attitudes. *Journal of Aging & Mental Health*, ***10***(6), 574-582.

MacLaren Chorney, J., McMurtry, M., Chambers, C. & Bakeman, R. (2015). Developing and Modifying Behavioral Coding Schemes in Pediatric Psychology: A Practical Guide. *Journal of Pediatric Psychology*, ***40***(1), 154-164.

Madara, E. J. (1997). The Mutual-Aid Self-Help Online Revolution. *Social Policy*, ***27***(3), 20-26.

Maddock, C., Lewis, I., Ahmad, K. & Sullivan, R. (2017). Online information needs of cancer patients and their organizations. *eCancermedicalscience*.

Malik, S. & Coulson, N. (2008a). The male experience of infertility: a thematic analysis of an online infertility support group bulletin board. *Journal of Reproductive and Infant PSychology*, ***26***(1), 18-30.

Malik, S. & Coulson, N. (2008b). Computer-mediated infertility support groups: An exploratory study of online experiences. *Patient Education and Counseling*, ***73***, 105-113.

Malik, S. & Coulson, N. (2010). Coping with infertility online: An examination of self-help mechanisms in an online infertility support group. *Patient Education and Counseling*, ***81***, 315-318.

Mangold, W. G. & Faulds, D. (2009). Social Media: The new hybrid element of the promotion mix. *Business Horizons*, ***52***, 357-365.

Manheim, L. (2014). Information non-seeking behavior. *Information Research,* ***19***(4).

Marshall, J. G. (1992). A development and evaluation model for a consumer health information service. *The Canadian Journal of Information Science*, ***17***(4), 1-17.

Martin, S. D. & Youngren, K. B. (2002). Help on the Net. Internet Support Groups for people dealing with Cancer. *Home Healthcare Nurse*, ***20***(12), 771-777.

Mattsson, S., Gustaf-Olsson, E. M., Alfonsson, S., Johansson, B. & Carlsson, M. (2015). Measuring the Use of Health-Related Support on the Internet: Development of the Health Online Support Questionnaire (HOSQ). *Journal of Medical Internet Research*, ***17***(11).

McEwan, B. (2016). ommunication of communities: linguistic signals of online groups. *Information, Communication & Society*, ***19***(9), 1233-1249.

McKenzie, P. J. (2003). Personal communication. N. Hernandez.

McMillan, S. J. & Hwang, J.-S. (2002). Measures of Perceived Interactivity: An exploration of the Role of Direction of Communication, User Control, and Time in Shaping Perceptions of Interactivity. *Journal of Advertising*, ***31***(3), 29-42.

McMullan, M. (2006). Patients using the Internet to obtain health information: How this affects the patient-health professional relationship. *Patient Education and Counseling*, ***63***(1), 24-28.

McTavish, F. Gustafson, D. H. Pingree, S. Hawkins, R. P. Owens, B. Wise, M., . . . Thorson, B. (1995). CHESS: An interactive computer system for women with breast cancer piloted with an underserved population. *Journal of Ambulatory Care Management*, ***18***(3), 35-41.

McTavish, F. M., Pingree, S., Hawkins, R. & Gustafson, D. (2003). Cultural differences in Use of an Electronic Discussion Group. *Journal of Health Psychology*, ***8***(1), 105-117.

Miles, M. B. & Huberman, M. A. (1994). *Qualitative Data Analysis: an expanded sourcebook*. Thousand Oaks: CA: Sage Publications.

Miller, B. (2010). Patients as Consumers? A Healthcare Cure? *Medicine Think. devise and revise.*

.

Miller, S. (1987). Monitoring and Blunting: Validation of a questionnaire to access styles of information seeking under threat. *Journal of Personality and Social Psychology*, ***52***, 345-353.

Miller, S., Summerton, J. & Brody, D. (1988). Styles of Copying with Threat: Implications for Health. *Journal of Personality and Social Psychology*, ***54***(1), 142-148.

Miller, S. M. (1979). Coping with impending stress: psychophysiological and cognitive correlates of choice. *Psychophysiology*, ***16***(6), 572-581.

Mishra, J., Allen, D. & Pearman, A. (2014). Information Seeking, Use, and Decision Making. *Journal of the American Society for Information Science and Technology.*

Mo, P. K., Malik, S. H. & Coulson, N. S. (2009). Gender differences in Computer-mediated communication: A systematic literature review of online health-related support groups. *Patient Education and Counseling*, ***75***, 16-24.

Mo, P. K. & Coulson, N. S. (2010). Empowering processes in online support groups among peopleliving with HIV/AIDS: A comparative analysis of 'lurkers' and 'posters'. *Computer in Human Behavior*, ***26***(5), 1183-1193.

Mo, P. K. & Coulson, N. S. (2013). Online support group use and psychological health for individuals living with HIV/AIDS. *Patient Education and Counseling,* ***93***(3), 426-432.

Monchaux, S., Amadieu, F., Chevalier, A. & Marine, C. (2015). Query strategies during information searching: effects of prior domain knowledge and complexity of the information problems to be solved. *Information Processing and Management*, ***51***, 557-569.

Moorhead, S. A., Hazlett, D. E., Harrison, L., Carroll, J. K., Irwin, A. & Hoving, C. (2013). A New Dimension of Health Care: Systematic Review of the Uses, Benefits, and Limitations of Social Media for Health Communications. *Journal of Medical Internet Research*, ***15***(4).

Morrow, P. (2006). Telling about problems and giving advice in an internet discussion forum: some discourse features. *Discourse studies*, ***8***(4), 531-548.

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L. & Buick, D. (2002). The revised illness perception questionnaire (IPG-R). *Psychology & Health*, ***17***(1), 1.

Munson, S. A., Cavusoglu, H., Frisch, L. & Fels, S. (2013). Sociotechnical Challenges and Progress in Using Social Media for Health. *joournal of Medical Internet Research*, ***15***(10).

Murray, E., Burns, J., See, T. S. & Nazareth, I. (2006). Interactive Health Communication Applications for People with Chronic Disease. *Cochrane Database of Systematic Reviews (online)*(1).

Nahl, D. & Tenopir, C. (1996). Affective and Cognitive searching behavior of Novice End-Users of a Full-Text Database. *Journal of the American Society for Information Science and Technology*, ***47***(4), 276-286.

Nahl, D. (1997). Infornation Counseling Inventory of Affective and Cognitive Reactions while Learning the Internet. *Internet Reference Services Quarterly*, ***2***(2-3), 11-33.

Nahl, D. (2001). A conceptual framework for explaining Information Behavior. *Studies in Media & Information Literacy Education*, ***1***(2), 1-16.

Nahl, D. (2006). A symbiotic human-machine model for tracking user micro-attributes. Hawaii International Conference on System Sciences (HICCS). Kawaii.

Nahl, D. (2007a). Social-biological information technology: an integrated conceptual framework. *Journal of the American Society for Information Science and Technology.*, ***58***(13), 2021-2046.

Nahl, D. (2007b). A discourse analysis technique for charting the flow of micro-information behavior. *Journal of Documentation*, ***63***(3), 323-339.

NationalCancerInstitute, (2013). Health Information National Trend Survey. Retrieved on, from http://hints.cancer.gov.

Neuendorf, K. A. (2016). *The Content Analysis Guidebook.* Thousand Oaks, CA: Sage Publications.

Newby, N. M. (1996). Chronic illness and the family life-cycle. *Journal of Advanced Nursing*, ***23***, 786-791.

Newman, M. W., Lauterbach, D., Munson, S. A., Resnick, P. & Morris, M. E. (2011). ""It's not that I don't have problems, I'm just not putting them on Facebook" : Challenges and Opportunities in Using Online Social Networks for Health." In Conference on Computer Supported Cooperative Work. New York, P. o. t. A. 2011, pp. ACM Press.

Nicholas, D., Huntington, P., Williams, P. & Blackburn, P. (2001). Digital health information provision and health outcomes. *Journal of Information Science*, ***27***(4), 265-276.

Nicholas, D., Huntington, P., Williams, P. & Gunter, B. (2003). Health Information and health benefit: A case of study of digital interactive television information users. *New Review of Information Behaviour Research*, ***4***(1), pp. 177-194.

Nicholas, D., Jamali, H., Huntington, P. & Williams, P. (2007). *Digital Health Information for the Consumer: Evidence and Policy Implications*. In Nicholas, D., Jamali, H., Huntington, P. & Williams, P. (Ed.).Great Britain: Ashgate.

Nickelson, D. (2000). Telecommunication trends and professional practice: opportunities and challenges. *Practitioner*, ***12***, 8-9.

NOCC, (2017). National Ovarian Cancer Coalition. Retrieved on April, 20, 2017, from http://ovarian.org/about-ovarian-cancer/what-is-ovarian-cancer).

Nolke, L., Mensing, M., Kramer, A. & Horngerb, C. (2015). Sociodemographic and health-(care) related characteristics of online health information seekers: a cross-sectional German study. *BMJ Public Health*, ***15***(31).

Norman, C. D. & Skinner, H. A. (2006). eHealth Literacy: Essential skils for consumers health in a networked world. *Journal of Medical Internet Research*, ***8***(2).

NTIA & ESA (2013). Exploring the Digital Nation: America's Emerging Online Experience. D. o. Commerce.

Nupur, T. (2010). The Role of Patient Satifaction in Online Health Information Seeking. *Journal of Health Communications*, ***15***, 3-17.

O'Brien, R., Hunt, K. & Hart, G. (2005). It's caveman stuff, but that is to a certain extend how guys still operate: Men's accounts of masculinity and help seeking. *Social Science and Medicine*, ***61***, 503-516.

Ogan, C. (1993). Listserver: communication during the Gulf War: what kind of medium is the electronic bulletin board? *Journal of Broadcasting and Electronic Media*, ***37***, 177-196.

Oh, H. J., Ozkaya, E. & LaRose, R. (2014). How does online social networking enhance life satisfaction? The relationship among online supportive interaction, affect, perceived social support, sense of community, and life satisfaction. *Computers in Human Behavior*, ***30***(1), 69-78.

Oprescu, F., Campo, S., Lowe, J., Andsager, J. & Morcuende, J. (2013). Online Information Exchanges for Parents of Children With a Rare Health Condition: Key findings from an Online Support Community*. Journal of Medical Internet Research*, ***15***(1).

Osiobe, S. A. (1985). Use of Information Resources by Health Professionals: A review o the Literature. *Social Science and Medicine*, ***21***(9), 965-973.

Owens, J. E., Boxley, L., Goldstein S., M., Lee, J. H., Breen, N. & Rowland, J. H. (2010). Use of Health-Related Online Support Groups: Population Data from the California Health Interview Survey Complementary and Alternative Medicine Study*. Journal of Computer-Mediated Communication*, ***15***, 427–446.

Palmquist, R. A. (2009). *Taylor's Information Use Environments*. In K. E. Fisher, S. Erdelez & L. Mckechnie (Eds.), *Theories of Information Behavior* (pp. Medford, New Jersey: Information Today.

Pan, L.-Y. & Chiou, J.-S. (2011). How much can you trust online information? Cues for perceived trusthworthiness of consumer-generated online information. *Journal of Interactive Marketing*, ***25***(2), 67-74.

Pang, P. C., Verspoor, K., Chang, S. & Pearce, J. (2015). Conceptualising health information seeking behaviors and exploratory search: result of a qualitative study. *Health and Technology.*

Park, C. & Lee, T. M. (2009). Information direction, website reputation and eWOM effect: a moderating role of product type*. Journal of Bussiness Research*, ***62***(1), 61-67.

Parthasarathy, F. & Fang, X. (2013). *Introducing Emotional Interfaces to Healthcare Systems*. In M. Kuroso (Eds.), *Human-Computer Interaction. Applications and services.* (pp. 150-162): Springer.

Patrick, K. & Koss, S. (Feb, 1996). *Consumer Health Information White Paper.* Department of Health and Human Services,

Pelz, D. (1978). *Some expanded perspectives on use of social science in public policy.* In Yinger & Cutler (Eds.), *Major social issues: a multidisciplinary view* (pp. 346-357). New York: Free Press.

Perloff, R. M. (2003). *The Dynamics of Persuasion: Communication and Attitudes in the 21st Century*. Mahwah, New Jersey: Lawrence Erlbaum Associates.

Peterson, M. W. & Fretz, P. C. (2003). Patient Use of the Internet for Information in a Lung Cancer Clinic. *Chest*, ***123***(2), 452-457.

Pettigrew, K. E., Raya, F. & Bruce, H. (2001). Conceptual Frameworks in Information Behavior. *Annual Review of Information Science and Technology*, ***35***, 43-78.

PewResearchCenter (2014) *Health Fact Sheet.* Internet, Science & Tech from http://www.pewinternet.org/fact-sheets/health-fact-sheet/

Pfeil, U. & Zaphiris, P. (2010). Applying qualitative content analysis to study online support communities. *Univ Access Inf Soc*, ***9***, 1-16.

Pifalo, V., Hollander, S., Henderson, C. L., DeSalvo, P. & Gill, G. P. (1997). The impact of consumer health information provided by libraries: the Delaware experience. *Bulletin of the American Library Association*, ***85***(1), 16-22.

Pollin, I. & Golant, S. (1994). *Taking charge: Overcoming the challenge of long-term illness.* New York: Ramdom House.

Powell, J., Inglis, N., Ronnie, J. & Large, S. (2011). The characteristics and motivations of online health information seekers: Cross-sectional survey and qualitative interview study. *Journal of Medical Internet Research*, ***13***(1).

Pritchard, M. (1974). Reaction to Illness in Long Term Haemodialysis. *Journal of Psychosomatic Research*, ***18***, 55-67.

Rafaeli, S. (1988). *Interactivity: From new media to communication.* In (Eds.), *Annual Review of Communication Research: Advancing Communication Science.* (pp. 110-134). Beverly Hills, CA.: Sage.

Rafaeli, S. (1997). Networked Interactivity*. Journal of Computer-Mediated Communication*, ***2***(4).

Rains, S. A. (2014). The implications of stigma and anonymity for self-disclosure in health blogs. *Health Communication*, ***29***(1), 23-31.

Rakowski (1990). Information-seeking about health in a community sample of adults: correlates and associations with other health-related practices. *Health Education Quaterly*, ***17***, 379-393.

Rakowski, W. Andersen, M. R. Stoddard, A. M. Urban, N. Rimer, B. K. Lane, D. S., . . . Costanza, M. E. (1997). Confirmatory analysis of opinions regarding the pros and cons of mammography*. Health Psychology*, ***16***(5), 433-441.

Raya, F. (2012). *What is Human Information Interaction?* In F. Raya (Eds.), *Human Information Interaction.* (pp. pp. 17-43). Cambrige, Massachussetts: MIT Press.

Rice, R. E. (2006). Influences, usage, and outcomes of Internet health information searching: Multivariate results from the Pew surveys. *International Journal of Medical Informatics*, ***75***, 8-28.

Ridings, C. M., Gefen, D. & Arinze, B. (2002). Some antecedents and effects of trust in virtual communities. *Journal of Strategic Information Systems*, ***11***(3-4), 271-295.

Ridings, C. M. & Gefen, D. (2004). Virtual Community Attraction: Why people Hang Out Online. *Computer-Mediated Communication*, ***10***(1).

Risk, A. & Petersen, C. (2002). Health Information on the Internet. *Journal of the American Medical Association*, ***287***(20), 2713-2715.

Robinson, T. N., Patrick, K., Eng, T. R. & Gustafson, D. H. (1998). An Evidence-Based Approach to Interactive Health Communication. A challenge to Medicine in the Information Age. *Journal of the American Medical Association*, ***280***(16), 1264-1269.

Roscoe, R. D., Grebitus, C., O'Brian, J., Johnson, A. C. & Kula, I. (2015). Online Information search and decision making: Effects of web search stance. *Computers in Human Behavior*, ***56***, 103-118.

Rosembaum, S. (2010). Data Governance and Stewardship:Designing Data Stewardship Entities and Advancing Data Access. *Health Services Research*, ***45***(5), 1442-1455.

Rosenberg, H. S. & Epstein, Y. M. (2001). *The Internet and Infertility.* In H. S. Rosenberg & Y. M. Epstein (Eds.), *Getting Pregnant when you thought you couldn't: the interactive guide that helps you up the odds.* (pp. 356-372). New York, NY: Warner Books.

Roter, D. (1984). Patient question asking in physician-patient interaction. *Health Psychology, **3***(5), 395-409.

Salem, D. A., Bogar, G. & Reid, C. (1997). Mutual Help goes Online. *Journal of Community Psychology*, ***25***(2), 189–207.

Savolainen, R. (2001). "Living encyclopedia" or idle talk? Seeking and providing consumer information in an Internet Newsgroup. *Library and Information Science Research*, ***23***, 67-90.

Savolainen, R. (2007). Information Behavior and Information Practice: Reviewing the "Umbrella concepts" of Information-Seeking Studies*. Library Quartely*, ***77***(2), 109-132.

Savolainen, R. (2009). Information use and information processing: comparison and conceptualizations*. Journal of Documentation*, ***65***(2), 187-207.

Savolainen, R. (2011). Requesting and providing information in blogs and internet discussion forums. *Journal of Documentation*, ***67***(5), 863-886.

Savolainen, R. (2015). The interplay of affective and cognitive factors in information seeking and use. *Journal of Documentation*, ***71***(1), 175-197.

Schoch, N. A. & White, M. D. (1997). A Study of the Communication Patterns of Participants in Consumer Health Electronic Discussion Groups. *Proceedings of the 60th ASIS Annual meeting,*, 280-292.

Seale, C. (2006). Gender accommodation in online cancer support groups. *Health*, ***10***(3), 345-360.

Sharf, B. F. (1997). Communicating Breast Cancer On-Line: Suport and Empowerment on the Internet*. Women & Health*, ***26***(1), 65-83.

Sharif, H., Ismail, S., Farooqi, S., Khan, M. T. & Gulzar, M. A. (2015). A Classiffication Based Framework to Predict Viral Threads. *PACIS 2015 Proceedings*.

Sharoda, P., Hong, L. & Chi, E. H. (2011). "Is Twitter a Good Place for Asking Questions? A Characterization Study." In Proceedings of the Fifth International AAAI Conference on Weblogs and Social Media. Barcelona, Spain, pp. 578-581. The AAAI Press.

Shultz, P. N., Stave, C., Beck, M. L. & Vassilopoulou-Sellin, R. (2003). Internet Message Board Use by Patients with Cancer and Their Families. *Clinical Journal of Oncology Nursing*, ***7***(6), 663-667.

Shuval, J., Javetz, R. & Shye, D. (1989). Self-Care in Israel: Physicians views and perspectives. *Social Science and Medicine*, ***29***(2), 233-244.

Sidell, N. L. (1997). Adult Adjustment to Chronic Illness: A review of the Literature. *Health & Social Work*, ***22***(1), 5-11.

Silence, E. (2013). Giving and Receiving Peer Advice in an Online Breast Cancer Support Group. *CyberPsychology, Behavior, and Social Networking*, ***16***(6), 480-485.

Sillence, E. (2013). Giving and Receiving Peer Advice in an Online Breast Cancer Support Group. *CyberPsychology, Behavior, and Social Networking,* ***16***(6), 480-485.

Slaugther, L. (2002). *Semantic Relationships in Health Consumer Questions and Physicians Answers: A Basis for Representing Medical Knowledge for Concept Exploration Interfaces*. (Doctoral dissertation). University of Maryland, Maryland.

Souden, M. & Rubenstein, E. L. (2010). "Listening to Patients: How Understanding Health Information Use Can Contribute to Health Literacy Constructs." In American Society for Information Science and Technology. Pittsburg, PA, pp.

Spink, A. & Cole, C. (2006). Human Information Behavior: Integrating Diverse Approaches and Information Use. *Journal of the American Society for Information Science and Technology*, ***57***(1), 25-35.

Sternberg, R. (2009). *Cognitive Phychology*. Wadsworth, Belmont, CA.

Stommel, M. & Wills, C. (2004). *Clinical Research. Concepts and Principles for Advanced Practice Nurses*. Philadelphia: Lippincott Williams & Wilkin.

Stommel, W. & Lamerichs, J. (2014). *Interaction in online support groups. Advice and beyond.* In H. E. Hamilton & W.-y. S. Chou (Eds.), *The Routledge handbook of language and health communications.* (pp. 198-211). New York: Routledge.

Stone, E. F. & Stone, D. L. (1990). Privacy in organizations: theoretical issues, research findings, and protection mechanisms. *Research in Personnel and Human Resources Management*, ***8***, 349-411.

Stromer-Galley, J. (2004). Interactivy-as-product and Interactivity-as-Process. *The Information Society*, ***20***.

Sudau, F., Friede, T., Koschack, J., Makedonski, P. & Himmel, W. (2014). Sources of Information and Behavioral Patterns in Online Health Fporums: Observational Study. *Journal of Medical Internet Research*, ***16***(1).

Sullivan, C. F. (2003). Gendered Cybersupport: A Thematic Analysis of two Online Cancer Support Groups*. Journal of Health Psychology*, ***8***(1), 83-103.

Sun, N., Rau, P. P. & Ma, L. (2014). Understanding lurkers in online communities: A literature review. *Computers in Human Behavior*, ***38***, 110-117.

Sundar, S. S., Rice, R. E., Kim, H.-S. & Sciamanna, C. N. (2011). *Online Health Information. Conceptual Challenges and Theoretical Opportunities.* In T. L. Thompson, R. Parrott & J. F. Nussbaum (Eds.), *The Routledge Handbook of Health Communication.* (pp. 181-202). New York: Routledge.

Sweetland, J. (2000). User's perceptions of the impact of information provided by a Consumer Health Information Service: an in-depth study of six users. *Health Libraries Review*, ***17***(2), 77-82.

Taylor, R. S. (1991). *Information Use Environments*. In B. Dervin & M. Voight (Eds.), *Progress in Communication Sciences X* (pp. 217-255). Norwood, NJ: Ablex Publishing Corp.

Taylor, S., Falke, R., Shoptau, R. & Lichtman, R. (1986). Social support, support groups and the cancer patient. *Journal of Consulting and Clinical Psychology*, ***54***, 577-583.

Tichon, J. G. & Shapiro, M. (2003). The Process of Sharing Social Support in Cyberspace*. CyberPsychology & Behavior.*, ***6***(2), 161-170.

Todd, R. J. (1999a). Utilization of Heroin Information by Adolescent Girls is Australia: A cognitive Analysis. *Journal of the American Society for Information Science.*, ***50***(1), 10-23.

Todd, R. J. (1999b). Back to our beginnings: information utilization, Bertram Brookes and the fundamental equation of information science. *Information Processing and management*, ***35***, 851-870.

Tustin, N. (2010). The Role if Patient Satisfaction in Online Health Information Seeking. *Journal of Health Communications*, ***15***, 3-17.

Urfels, C. (2000). *Information Problem-Solving in Personal High-Stake Situations*. (Doctoral Thesis). Syracuse University, Syracuse, NY.

Vakkari, P. (1997). "Information seeking in context: a challenging metatheory." In Information Seeking in Context:proceedings of an International Conference on Research in Information needs, seeking and use in different context. P. Vakkari, R. Savolainen & B. Dervin, pp. Taylor Graham.

Van Der Molen, B. (1999). Relating Information needs to the Cancer experience: 1. Information as a coping strategy. *European Journal of Cancer Care*, ***8***, 238-244.

Van Deusen, A. J. & Van Dijk, J. A. (2009). Using the Internet: skill related problems in users' online behavior. *Interacting with Computers*, ***21***, 393-402.

Van Uden-Kraan, C. F., Drossaert, C. F., Taal, C. H., Lebrun, C. E., Drossaert-Bakker, K. W., Smith, W. M. & Van de Laar, M. A. (2008). Coping with somatic illnesses in online support groups: Do the feared disadvantages actually occur? *Computers in Human Behavior*, ***24***(2), 309-324.

Van Uden-Kraan, C. F. & Drossaert, C. H. C. (2008). Empowering Processes and Outcomes of Participation in Online Support Groups for Patients with Breast Cancer, Arthritis, or Fibromyalgia. *Qualitative Health Research*, ***18***(3), 405-417.

Van Uden-Kraan, C. F., Drossaert, C. H., Taal, C. H., Shaw, B. R., Seydel, E. R. & Van de Laar, M. A. (2009). Participation in online patient support groups endorses patients' enpowerment. *Patient Education and Counseling*, ***74***, 61-69.

Verhoeven, A., Boerma, E. & Meyboom-de, J. B. (1995). Use of information sources by family physicians: a literature survey. *Bulletin of the Medical Library Association*, ***83***(1), 85-90.

Vogt, W. P. (1999). *Dictionary of Statistics and Methodology.* Thousand Oaks, CA: Sage Publications.

Wagner, T. H. & Hibbard, J. H. (2001). Who Uses Self-Care Books, Advice Nurses, and Computers for Health Information? *International Journal of Technology Assessment in Health Care*, ***17***(4), 590-600.

Wagner, T. H., Hu, T.-W. & Hibbard, J. H. (2001). The demand for Consumer Health Information. *Journal of Health Economics*, ***20***, 1059-1075.

Wagner, T. H., Baker, L. C., Bundorf, K. & Singer, S. (2004). Use of the Internet for Health Information by the Chronically Ill. *Preventing Chronic Disease. Public Health Research, Practice, and Policy*, ***1***(4), 1-13.

Walsham, G. (1993). *Interpreting Information Systems in Organizations.* Chichester: Wiley.

Walther, J. B. (1992). Interpersonal effects in computer-mediated interaction: A relational perspective. *Communication Research*, ***19***(1), 52-90.

Wang, Y., Kraut, R. & Levine, J. M. (2012). "To Stay or Leave? The Relationship of Emotional and Informational Support to Commitment in Online Health Support Groups." In CSCW. Seattle, Washington, pp. ACM.

Webb, T. L., Joseph, J., Yarley, L. & Michie, S. (2010). Using the Internet to promote health behavior change: A systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. *Journal of Medical Internet Research*, ***6***(4), e40.

Weber, R. P. (1990). *Basic Content Analysis*. Newbury Park, CA: Sage.

Weinberg, N., Schmale, J., Ukan, J. & Wessel, K. (1995). Computer-mediated support groups. *Social Work with Groups*, ***17***(4), 43-54.

Weinberg, N., Schmale, J., Uken, J. & Wessel, K. (1996, "Online Help: Cancer Patients Participate in a Computer-Mediated Support Group." *National Association of Social Workers*, pp. 24-29

Weis, J. (2003). Support Groups for Cancer Patients. *Support Cancer Care*, ***11***, 763-768.

Weisgerber, C. (2004). Turning to the Internet for help on sensitive medical problems. *Information, Communication & Society*, ***7***(4), 554-574.

Wellman, B. & Gulia, M. (1999). *Virtual Communities as communities. Net surfers don't ride alone.* In M. A. Smith & P. Kollock (Eds.), *Communities in Cyberspace* (pp. London and New York: Routledge.

Westbrook, L. (1993). User needs: A synthesis and Analysis of Current Theories for the Practitioner. *RQ*, ***32***(4), 541-549.

White, M. D. (1998a). Questions in Reference Interviews. *Journal of Documentation*, ***54***(4), 443-465.

White, M. D. (1998b). Communication behavior on consumer-health electronic lists. *Internet Research*, ***8***(4).

White, M. D. (2000). Questioning Behavior on a Consumer Health Electronic List. *Library Quarterly*, ***70***(3), 302-334.

White, M. H. & Dorman, S. M. (2000). Online Support for Caregivers. Analysis of an Internet Alzheimer Mailgroup. *Computers in Nursing*, ***18***(4), 168-176.

White, M. H. & Dorman, S. M. (2001). Receiving Social Support Online: Implications for Health Education. *Health Education Research*, ***16***(6), 693-707.

WHO, (2017). World Health Organization. Sexual and reproductive health. Retrieved on April, 20, 2017, from www.who.int/reproductivehealth/topics/infertility/definitions/en.

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

Wilson, T. D. (1981). On User Studies and Information Needs. *Journal of Documentation*, ***37***(1), 3-15.

Wilson, T. D. (1994). *Information Needs and Uses: Fifty Years of Progress?* In (Eds.), *Fifty years of Information Progress: A Journal of Documentation Review* (pp. 15-51). London: Aslib.

Wilson, T. D. & Walsh, C. *Information Behavior: An Interdisciplinary Perspective*. The British Library Board,

Wilson, T. D. (1997a). "Information Behavior: An Interdisciplinary perspective." In Information Seeking in Context: Proceedings of an International Conference on Research in Information Needs, Seeking and Use in Different Contexts. Tampere, Finland, pp. 39-49. London: Taylor Graham.

Wilson, T. D. (1997b). Trends In … A critical Review. *Information Processing and Management*, ***33***(4), 551-572.

Wilson, T. D. (1999). Models in Information Behavior Research. *Journal of Documentation*, ***55***(3), 249-270.

Wilson, T. D. (2000). Human Information Behavior. *Informing Science*, ***3***(2), 49-55.

Wilson, T. D. (2006). Revisiting user studies and information needs. *Journal of Documentation*, ***62***(6), 680-684.

Winzelberg, A. J. (1997). The Analysis of an Electronic Support Group for Individuals With Eating Disorders. *Computers in Human Behavior*, ***13***(3), 393-407.

Wright, K. B. & Bell, S. B. (2003). Health-related Support Groups on the Internet: Linking Empirical Findings to Social Support and Computer-mediated Communication Theory. *Journal of Health Psychology*, ***8***(1), 39-54.

Wright, K. B., Johnson, A. J., Bernard, D. R. & Averbeck, J. (2011). *Computer-Mediated Social Support. Promises and Pitfalls for Individuals Coping with Health Concerns.* In T. L. Thompson, R. Parrott & J. F. Nussbaum (Eds.), *The Routledge Handbook of Health Communication* (pp. 349-362). New York: Routledge.

Wright, K. B. & Rains, S. A. (2013). Weak-tie support network preference, health related stigma, and health outcomes in computer-mediated support groups. *Journal of Applied Communication Research*, ***41***(3), 309-324.

Wright, K. B. (2016). Communication in Health-Related Online Social Support Groups/ Communities: A Review of Research on Predictors of Participation, Applications of Social Support Theory, and Health Outcomes. *Review of Communication Research*, ***4***, 65-87.

Yates, C., Stoodley, I., Partridge, H., Bruce, C. & Cooper, H. (2012). Exploring Health Information Use by Older Australians within Everyday Life. *Library Trends*, ***60***(3), 460-478.

Ybarra, M. L. & Suman, M. (2006). Help seeking behavior and the Internet: A national survey. *International Journal of Medical Informatics*, ***75***, 29-41.

Ye, Y. (2011). Correlates of consumer trust in online health information: findings from the health information national survey. *Journal of Health Communications*, ***16***(1), 34-49.

Zhang, J. Q., Craciun, G. & Shin, D. (2010). When does electronic work-of-mouth matter? A study of consumer product reviews. *Journal of Bussiness Research*, ***63***, 1336-1341.

Zhang, Y. & Fu, W.-T. (2011). *Designing Consumer Health Information Systems: What do User-Generated Questions Tell Us?* In (Eds.), *Foundations of Augmented Cognition.* (pp. 536-545).

Zrebiec, J. F. & Jacobson, A. M. (2001). What attracts patients with diabetes to an Internet support group? A 21-month longitudinal website study. *Diabetic Medicine*, ***18***, 154-158.

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