



## Differences among breast and prostate cancer online support groups

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### ABSTRACT

Online support resources have become viable alternatives to face-to-face support groups for cancer patients. It is important to understand how individuals make use of such online support resources and what, if any, differences exist between groups. A content analysis was conducted on 3203 posted messages to prostate and breast cancer support sites on Google Groups and WebMD. Overall, post-treatment survivors were the most common posters followed by spouses; however, the proportion of posters varied by site. For both groups, messages of support were most frequent. However the type of support varied by cancer type. Support messages on the breast cancer sites were mostly offers of emotional support. Conversely, messages of support on the prostate cancer sites focused on informational support. Messages of emotional well-being and medical-related comments were next most common on the breast cancer sites, whereas medical issues and sexual intimacy were on the prostate cancer sites. Overall, these findings identify several key differences in the use and benefits of online support sites for breast and prostate cancer.

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### 1. Introduction

Serious health conditions often lead people (including patients, family members, and other loved ones) to join support groups in an effort to cope with the associated stress (Alexander, Peterson, & Hollingshead, 2003; Barrera, Glasgow, McKay, Boles, & Feil, 2002; Davison, Pennebaker, & Dickerson, 2000; Klemm et al., 2003; Munce, Loader, Burrows, Pleace, & Nettleton, 2001; van Uden-Kraan et al., 2008). With the growth and accessibility of the Internet, online support groups and information resource sites have become viable alternatives to face-to-face support groups. To this end, it is important to understand how the members of these groups interact with and make use of such online support resources and what, if any, differences exist between groups.

Unique advantages of such resources include greater accessibility (lack of time and travel constraints), anonymity, and the ability to obtain information without having to personally interact with others (Broom, 2005; Finfgeld, 2000; van Uden-Kraan et al., 2008). These benefits are likely to carry significant weight for newly diagnosed cancer patients. For instance, health risks associated with having a compromised immune system can result in confinement to the home as a protective measure and make attending in-person support groups impossible. Also, Davison, Pennebaker, and Dickerson (2000) found in their analyses of face-to-face and online support groups that patients of diseases considered to be stigmatizing (e.g. breast and prostate cancer) were more likely to seek

support compared with other life-threatening but less stigmatizing diseases (e.g. heart disease). Thus, because of the possibility of home confinement due to a compromised immune system and the potential emotional turmoil experienced from being diagnosed with a stigmatized disease, some survivors of breast and prostate cancer may be more comfortable in the remote and anonymous involvement of online support groups.

These asynchronous “communities” provide access to information, social comparison, and support and are accessible via computer and other Internet accessible devices 24 h a day. This information is especially important with the diagnosis of a disease such as cancer, when one has questions about treatment choices, how to make decisions, getting a sense of what is to come, and where to get additional information and support (Holland & Lewis, 2001; King & Moreggi, 1998; Rice & Katz, 2001). Alexander et al. (2003) claim that social support is exchanged in these online sites in at least four main forms: information support, emotional support, esteem support, and tangible assistance. In several prior studies which analyzed a variety of cancer support groups, information support was found to be the predominant type of support exchanged (Alexander et al., 2003; Gooden & Winefield, 2007; Klemm, Hurst, Dearholt, & Trone, 1999; Meier, Lyons, Frydman, Rimer, & Forlenza, 2007).

Breast cancer and prostate cancer groups are the focus of attention in this study. They were selected for several reasons. First, both are common cancers as the second and third most commonly diagnosed cancers in the US behind lung cancer. In 2009, estimates of new diagnoses of prostate and breast cancers were between 190,000 and 195,000 each (American Cancer Society, 2009).

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Second, each of these diseases is gender specific, with 100 percent of prostate cancer patients being male, and about 99 percent of breast cancer patients being female, allowing for comparisons related to gender of patient (as will be reviewed below). Evidence shows that the support needs of those diagnosed and their families vary by disease (e.g., Blank & Adams-Blodnieks, 2007; Gooden & Winefield, 2007; Klemm et al., 1999). However, to date, it is unclear how much of these differences can be attributed to the gender composition of each disease group or to the particular treatments and impacts of each type of cancer. Also, it is important to know whether cohort changes in gender-based cancers or new technological modalities for communication are changing the relatively strict gendering of the diseases and communication about them that was found in the past. A pragmatic reason is that there are very active online groups that provide many messages to enable analysis.

Regarding the use of online support for men diagnosed with prostate cancer and women diagnosed with breast cancer, differences have been found. However, there are conflicting speculations as to the source of these differences, some having to do specifically with the gendered nature of the cancer sites. Specifically, prostate cancer survivors have been found to utilize online support sites primarily for information gathering, while breast cancer survivors are noted to use these sites as sources of emotional support (Blank & Adams-Blodnieks, 2007; Mo, Malik, & Coulson, 2009; Owen, Klapow, Roth, & Tucker, 2004; Seale, Ziebland, & Charteris-Black, 2006). However, research on mixed gender support sites has failed to find these gender differences (Mo et al., 2009). Moreover, Seale (2006) noted that men participating on breast cancer support sites have adopted a more emotional style of communication, but women participating on prostate cancer sites were not observed to accommodate their writing to the dominant gender.

Competing theories for these findings have been postulated. On the one hand, Owen et al. (2004) suggest that underlying gender differences is the primary contributor to the observed differences. Social role theory (Eagly, 1997) posits that cultural expectations for the appropriateness of gender-related behaviors derive from the division of labor in society. In essence, men are groomed to be agentic and instrumental; whereas, women are socialized to be communal and emotionally expressive. Related to this theory, it may be that men and women are utilizing and communicating on online sites in socialized gender-appropriate ways. Furthermore, Mo et al. (2009) noted that the gender composition of the community (or online membership) may dictate the different patterns of behaviors observed on these Internet sites. However, Seale (2006) finding that women who participate on prostate specific sites do not alter their behaviors appears to contradict this latter hypothesis.

On the other hand, it has been put forth that the particulars of each type of cancer may be the primary factors leading to the observed differences in the two groups (Mo et al., 2009; Seale et al., 2006). These may or may not have to do with the gendered nature of the diseases, in that treatment sequelae have to do with erectile function on the part of prostate cancer and breast in breast cancer. Beyond this, the more difficult decisions about prostate cancer and less well-defined treatment options may result in prostate cancer patients seeking out disease specific information to aid them in making better informed decisions. Likewise, breast cancer treatment options are more clearly defined and widely accepted, which can allow patients to prioritize the emotional and social support aspects on online cancer sites (Mo et al., 2009; Owen et al., 2004; Seale et al., 2006).

In sum, cancer survivors and those who care about them are increasingly relying on the Internet for information and support; yet, the reasons and benefits for accessing Internet support sites differs for prostate and breast cancer patients and survivors. The

purpose of this study is to add to this current body of knowledge regarding how online cancer groups are used for communicating cancer treatment information, social and emotional support, and survivorship issues. Although the previous research noted has examined some of these facets, including comparisons of breast and prostate cancer, the ever-changing nature of online communication and the potentially different styles and audiences at different online sites make it important to expand the past information both temporally and in relation to specific online sites. To accomplish the aims of this study, a content analysis was conducted on a large set of messages from two different Internet websites, each with separate messaging boards for prostate and breast cancer and different from that examined previously by this investigator. In particular, this research focuses on who are the most common posters (e.g., long-term survivors, newly diagnosed patients, spouses, etc.) and how different types of message content (e.g., medical, intimacy, emotional, support) differ between prostate cancer and breast cancer groups.

## 2. Method

### 2.1. Procedures and participants

WebMD and Google Groups are Internet resources that are used by people looking for information and support regarding breast cancer and prostate cancer. Google Groups is a free Internet discussion service. Groups are distinguished based on a topical common interest and communication within these groups is through individual postings that all members of the group can read and respond to if so desired. WebMD is a public Internet site that provides services and information on many health-related issues for both patients and medical professionals. Among the services offered by WebMD are electronic message boards which allow individuals to post, read, and respond to messages in online discussions.

Online support group messages in both prostate and breast cancer groups from Google Groups and WebMD were obtained over a one month period, which were examined and coded according to content. Both messages that began discussions and responses were included in the analysis. There were a total of 3203 postings that were coded and included in the analysis. A total of 1987 postings came from WebMD (62.0%) and 1216 came from Google Groups (38.0%). Including both WebMD and Google Groups there were 2168 messages posted in the breast cancer sites (67.7%) and 1035 postings on the prostate cancer sites (32.3%). Many postings addressed two or more specific issues and they fell into more than one subcategory; thus, out of the 3203 messages posted, there was a total of 5149 main category codings and 6102 subcategory codings identified. The multiple coding of an individual posting obviously presents problems with analyses assuming independence. However, since it is impossible to know which category was the more prominent in the mind of the sender (or reader) and in order to reflect as much as possible the range of information that presents itself to readers of the sites, multiple category codings were retained. It should be noted that the majority of messages received one coding, and only a small percent included more than two. Likewise, some individuals contributed more than one message. All messages were included, for several reasons. The most important is that any individual reader would be exposed only to a relatively small percentage of all the comments, because he or she “jumped in” to the ongoing discussion at a specific time. It is likely that he or she is focused more on the content of the message than on the screen name of who sent it. Restricting the sampling to only one or a limited number of messages from a single contributor biases the analyses in a different way, because it would not reflect the

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