

Chapter 58

Cyber Support Venues for Cancer

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ABSTRACT

In recent years, many cancer patients and families have turned to the Internet for information and support. Cyber support venues to serve those needs vary from small newsgroups to discussion areas as part of comprehensive eHealth support systems. Two decades of research studies, mostly on breast and/or prostate cancer venues, indicate a range of users, including both patients and family members, and reveal both advantages and disadvantages compared to face-to-face support groups. Researchers have shown consistent differences about how breast and prostate sites are used, apparently due to both gender-based approaches to communication and support and different issues related to the different cancer types. Limited research indicates mostly positive psychological well-being impacts of participating on these venues. Future research is needed to further explore gender differences and examine how newer cyber venues, such as blogs, Facebook, and Twitter, become utilized by those facing cancer.

INTRODUCTION

The advent of the Internet at the end of the twentieth century and technological advances that have followed have made electronic health (eHealth) information and support venues accessible and user-friendly to a large number of individuals.

Although the costs of computer ownership and Internet access may be prohibiting factors for some, free Internet access at libraries, schools, and other accessible locations does, to some degree, minimize this barrier. By the mid-1990s, only 10% of adults in America had access to the Internet; in 2010, that number rose to 75% for adults and 95% for teenagers (Fox, 2010). Additionally, 80% of adult caregivers have Internet access. Only

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20 years ago, most persons dealing with a major disease needed to visit a library or bookstore to peruse the limited resources available; however, today most need only spend a few minutes with an Internet search engine to have access to a vast array of information (often times an overload of information). Whereas 20 or more years ago, the primary sources of social support were family and friends or the occasional contact with someone who had dealt with something similar, today those persons can easily make contact with others and obtain information and support through the Internet, as well as a network of traditional face-to-face groups. Researchers in health communications, stress and coping, and mental health have attempted to keep pace with the changing environment through research on how cyber-space is used by those diagnosed with and living with a chronic health condition or disease (in this case cancer) and the impact that such online use may have on their understanding of and adaptation to their condition. This is part of the much larger area of eHealth.

It is difficult to define the focus of this entry, given the wide variety of approaches taken to providing support environments online for those who are dealing with cancer. In fact, it has proven difficult even to label the topic accurately. Many who have studied this range of information and support, including us in several articles, have referred to the category as “online cancer support groups.” However, it is clear that “support groups” has a connotation that is not directly relevant for many of the sites. For example, from the point of view of more traditional, non-Internet-based support groups, there are some important common elements: 1) they are composed of people who share a specific characteristic, such as alcoholism, grief, or, in the case of our focus, a specific health condition such as cancer, and 2) they are at least primarily face-to-face, and, thus, synchronous with direct dialogue whether that be with others who share the characteristic or in a question and answer format with professionals who may

be managing the support group. We should note that there are also considerable variations in such typically-defined support groups such as whether there is a professional provider present for consultation or information, whether family members are included, and so on. However, online venues, by their nature, cannot control who participates (especially who may “lurk”), and they are generally asynchronous. They include and are variously labeled as bulletin boards, computer-based support networks, newsgroups, listservs, discussion groups, online communities, and support groups. Very recently, one of the most prolific research teams in the area (Baker et al., 2011) has used a term “Interactive Cancer Communication Systems” as their label for a broader set of cancer-related sites that incorporate a system for cancer patients and survivors to share their feelings and obtain information and support.

Upon review of the various uses of these sites, we decided to adopt a somewhat broader label for this discussion that connects the cyber-behavior aspect with the idea of providing information and support of various sorts to those who are concerned with cancer and its impact—“cyber support venues for cancer.” We define these as online environments that provide for synchronous and/or asynchronous sharing of information, discussion, and support related to cancer. These venues directly address the needs of cancer patients and survivors with information about treatments and their effects, opportunity for emotional and social support, and exchange of experiences.

The area encompasses a wide range of sites, from ones narrowly-defined and solely having to do with one specific cancer (e.g., www.yananow.net) to ones embedded in much larger, more all-encompassing health sites (e.g., www.webmd.com), to ones that have a discussion/sharing area as part of a more static informational site related to cancer (e.g., CHESS—Comprehensive Health Enhancement Support System), to ones that are peer-based communication exchanges (e.g., newsgroups & listservs) within the Internet universe

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