

Cancer Patient-to-Patient Online Discussion Groups

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INTRODUCTION

Three high-level observations set the stage:

- Cancer is a major cause of death
- Health-related concerns drive the greatest use of the Internet (Eysenbach, 2003)
- Cancer patients may find support from online discussion groups.

Actually, these discussion groups are for more than patients. Definitions of the users of the discussion systems and the types of systems are presented next.

Care givers are those people who help a patient as friends or family of the patient (this is in contrast to care providers, who are healthcare professionals). The discussion systems to be addressed here serve both care givers and patients, and sometimes a more extended group of people who want to help or otherwise be involved in cancer support. This extended group of people will be denoted by the term 'patient' throughout the remainder of this article.

The first patient online discussion system benefited from early technology to exploit e-mail connections known as e-mail list servers (listservs). A listserv allows a group of people to communicate by e-mail through a common email address. The listserv stores the messages received and participants can either receive e-mails one by one as they are sent, or in digests at daily, weekly or monthly intervals. Moderators are typically assigned to listservs and may determine conditions for membership in the listserv. The listserv itself has features for people to request enrollment and search the archives. Following the popularity of the World Wide Web (Web), technologists implemented Web discussion systems that allow people to register on the Web and gain access to Web-based archives of messages. These Web discussion systems typically also incorporate all the features of a listserv.

Cancer patients participating in various online discussion systems will next be studied according to:

- Patient patterns of use
- Impact of the discussion systems on the patients

- The extent to which patients might make scientific discoveries
- The role of different healthcare industry entities in the management of these discussion systems

The reader will see the opportunities for extended use of these discussion systems.

PATTERNS OF USE

Although the psychological distress of most cancer patients improves over time, many experience clinically significant distress and poorer well being long after diagnosis (Ell, Nishimoto, Morvay, Mantell & Hamovitch, 1989). Patients may turn to the Internet and one another for help. Eighty percent of adult, American Internet users have searched for health topics online (Fox & Fallows, 2003). Long-time Internet users are more likely to search for information about a specific disease than newcomers. When counting the tens of millions of Americans who actively use online health resources, researchers should calculate a much larger 'zone of influence,' made up of friends, family members, co-workers and neighbors who also benefit. Healthcare is often a highly social, not solitary, activity.

Cancer patients have different needs at different times in the course of their cancer experience: Patients want information in the first phase, when they learn about their cancer and the treatment alternatives; later, patients are more interested in empathy and, overall, the dominating use of these discussion systems is for emotional support (Arnold, Leimeister, & Krcmar, 2003). Typically, a few patients contribute the majority of messages to a particular discussion system.

IMPACT

American healthcare is increasingly adopting the consumer perspective, although at times this strains relationships between patient and doctor (Coombs, Hereford & LePore, 2001). A survey of information needs of cancer patients revealed that one-on-one dialog with the doctor or nurse was the preferred source of information

for most patients (Lock & Willson, 2002). However, the Internet was a popular alternative for these patients, and providing as much one-on-one information as patients would like may not be practical to achieve through doctors and nurses alone. Overall, 73% of health seekers say the Internet has improved the medical information and services they receive.

The Breast Cancer List was created in 1994 because breast cancer patients expressed a desire for it and no comparable service existed. The listserv attracted hundreds of participants and is considered a valuable resource. The usefulness and popularity of online support translates into enthusiasm from patients for electronic communication. The breast cancer patients describe the value of the listserv in both emotional and practical terms. On the emotional side, empathy is highly valued, and giving support is as important as getting it. On the practical side, support leads to tangible results (Sharf, 1997).

Patients gain needed support through patient-to-patient discussion systems (Fawzy, Cousins, Fawzy, Kemeny, Elashoff, & Morton, 1990). However, despite evidence of the effectiveness of discussion groups, many patients do not participate. In one study, only 10% of the breast cancer patients from a private practice attended cancer support groups, and most dropped out because the groups did not meet their needs (Taylor, Falke, Shoptaw, & Lichtman, 1986). Practical problems involve difficulties attending meetings, including a lack of transportation, a far distance to travel or inconvenient meeting times. Medical factors center on the impact of the illness; for example, cancer patients may be too weak or too sick to attend meetings.

The potential advantages of the online group include allowing patients to participate in a group at a time of their choosing without leaving home and with the option of identifying themselves by a pseudonym and thus remaining anonymous. Cohen, Doyle, Skoner, Rabin, and Gwaltney (1997) proposed that social support affects health and mortality through a number of mechanisms, including:

- improved health behaviors
- decreased negative effect
- improved immune system functioning

Considering the stresses associated with cancer and the low participation rate of cancer patients in face-to-face support groups, one might expect online groups to fill a need.

Community is more easily found, chosen or started online (Madara, 1997). Furthermore, individuals with

chronic illnesses or disabilities might find it more convenient to participate in online support groups than participating in person. In virtual support groups, contributors are valued for the strength of their contributions rather than being evaluated on their physical appearance or disabilities. Online support groups are not limited by a local community's size, geography or social services. Internet-based support groups could help efforts to eliminate disparities in health that exist because of inequities in people's access to healthcare facilities.

PATIENT DISCOVERY

Patients are a source of information about how to improve medical care. Listening to patients is one way to reduce errors in medical care (Cleary, 2003). Patients may also make discoveries. For instance, in 1994, Norman Scherzer's wife, Anita, developed an abdominal tumor. Scherzer joined an online patient-to-patient discussion system for that disease. Through the list, Scherzer heard of a cancer specialist that was using a newly developed enzyme test to help diagnose tumors like Anita's. Their own doctor knew nothing about it, so he took his wife to see this new physician. Anita's cancer was correctly diagnosed as gastrointestinal stromal tumor (GIST). Scherzer started a new mailing list for GIST patients, the Life Raft Group (liferaftgroup.org). Scherzer learned that Gleevec was a trial treatment for GIST, and it was used on his wife successfully. In 2001, the Life Raft Group published in a peer-reviewed medical journal about Gleevec's side effects. Patient groups hold a unique and valuable position in research because of their numbers and an intense focus on their shared illness (Ferguson, 2002).

Prostate cancer is an example of a condition that invites patient-centric treatment decision making. In a survey of hundreds of urologists and radiation oncologists, the most dramatic difference between these two groups of specialists is that members of each specialty tend to believe in the therapy that they themselves deliver. Radiation oncologists tend to believe that their therapy is just as good as radical prostatectomy for men with moderately differentiated, clinically localized cancer, while urologists are overwhelmingly convinced that radical prostatectomy is better (Fowler, Collins, Ablertsen, Zietman, Elliott, & Barry, 2000). Since patients with surgery have a higher risk of sexual dysfunction and incontinence, the patient should know the full picture before making a decision.

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