Patients’ Attitudes Toward Internet Cancer Support Groups

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Purpose/Objectives: To explore patients’ attitudes toward Internet cancer support groups (ICSGs) through an online forum.

Research Approach: Qualitative study using a feminist perspective.

Setting: Internet and real settings.

Participants: 16 patients with cancer.

Methodologic Approach: An online forum was held for one month with six discussion topics. The data were analyzed using thematic analysis.

Main Research Variables: Attitudes toward ICSGs.

Findings: Through the data-analysis process, four themes were found related to patients’ attitudes toward ICSGs. First, the participants universalized patients’ needs for and attitudes toward ICSGs. Second, most of the participants wanted to use ICSGs for emotional support, information, and interactions. Third, many of the participants used ICSGs because they could reach out to other patients with cancer without traveling and without interrupting their busy schedules. Finally, many participants were concerned about the security of interactions on ICSGs, so they wanted ICSGs that could ensure privacy and safeguard the anonymity and confidentiality of what they shared online.

Conclusions: Patients view ICSGs positively. Additional studies should examine gender-specific and multilanguage ICSGs by recruiting more minority patients.

Interpretation: Despite concerns about the security of Internet interactions, ICSGs would be an excellent source of social support that is acceptable to patients with cancer.

Little is known about patients’ attitudes toward Internet cancer support groups (ICSGs). The few studies that have been conducted indicate that patients view ICSGs positively as a source of support and that patients’ use of health information and groups on the Internet increases social support by reducing social isolation and increasing personal empowerment and self-esteem (Fernsler & Manchester, 1997; Fogel, Albert, Schabel, Ditkoff, & Neugut, 2002a, 2002b, 2003; Gustafson, Wise, McTavish, & Taylor, 1993; Gustafson, Hawkins, Pingree, McTavish, & Arora, 2001; Houston, Cooper, & Ford, 2002; Klemm, Reppert, & Visich, 1998; Lieberman, Golant, & Giese-Davis, 2003; McTavish, Gustafson, & Owens, 1995; Sharf, 1997; Weinberg, Schmale, Uken, & Wessel, 1996; Winzelberg, Classen, & Alpers, 2003). Participation in ICSGs also has been reported to reduce depression and cancer-related trauma (Houston et al., 2000; Satterlund, McCaul, & Sandgren, 2003; Ziebland et al., 2001; Pereira, Koski, Hanson, Bruera, & Mackey, 2000; Satterlund, McCaul, & Sandgren, 2003; Ziebland et al., 2004). Other studies, however, have reported that only 7%–10% of patients with cancer actually were meeting their needs for information or support through the Internet, and the patients were undecided about the trustworthiness of the medical information they could find online (Diefenbach et al., 2002; Mills & Davidson, 2002; Pereira et al.; Raupach & Hiller, 2002).

Studies have indicated gender and ethnic differences in ICSG use (Klemm, Hurst, Dearholt, & Trone, 1999; Pautler et al., 2001; Pereira, Koski, Hanson, Bruera, & Mackey, 2000; Satterlund, McCaul, & Sandgren, 2003; Ziebland et al., 2004). Other studies, however, have reported that only 7%–10% of patients with cancer actually were meeting their needs for information or support through the Internet, and the patients were undecided about the trustworthiness of the medical information they could find online (Diefenbach et al., 2002; Mills & Davidson, 2002; Pereira et al.; Raupach & Hiller, 2002).

Patients’ attitudes toward ICSGs also can be inferred from some of the findings on attitudes toward Internet use in general. Some patients with cancer go online to look for information related to their cancer, are willing to use the Internet for information and emotional support, and generally find the cancer-related information on the Internet to be useful (Pautler et al., 2001; Pereira, Koski, Hanson, Bruera, & Mackey, 2000; Satterlund, McCaul, & Sandgren, 2003; Ziebland et al., 2004). Other studies, however, have reported that only 7%–10% of patients with cancer actually were meeting their needs for information or support through the Internet, and the patients were undecided about the trustworthiness of the medical information they could find online (Diefenbach et al., 2002; Mills & Davidson, 2002; Pereira et al.; Raupach & Hiller, 2002).

Female participants expressed appreciation of gender-specific Internet cancer support groups (ICSGs) because they wanted to share the “women things” that men could not understand.

A common perception among the participants, who were mostly white, was that ethnic minority patients with cancer would not have difficulties using existing ICSGs if the groups supported diverse languages.

The time flexibility in ICSGs helped participants join and participate.

ICSGs were perceived as convenient by most of the participants because they could reach out to other patients with cancer while maintaining anonymity.

Key Points . . .

- Female participants expressed appreciation of gender-specific Internet cancer support groups (ICSGs) because they wanted to share the “women things” that men could not understand.
- A common perception among the participants, who were mostly white, was that ethnic minority patients with cancer would not have difficulties using existing ICSGs if the groups supported diverse languages.
- The time flexibility in ICSGs helped participants join and participate.
- ICSGs were perceived as convenient by most of the participants because they could reach out to other patients with cancer while maintaining anonymity.

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