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Comparing Messages in an Online Communication Forum for Cancer Patients with Patients' Messages to a Clinical Nurse Specialist

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Abstract

WebChoice is an online support system where cancer patients can exchange messages with other patients in an open communication forum as well as send personal e-mails to a clinical nurse specialist (CNS) who responds to their concerns. We compared the content of messages posted in the open forum with personal e-mail messages sent to the nurse. While patients were concerned with similar topics in both communication areas, there were differences in the types of messages sent. More patients actively used the patient-nurse email service compared to the forum, suggesting that nurses can play an important role in online systems supporting cancer patients over the Internet.

Keywords:

online systems, communication, nurse-patient relations, neoplasms

Introduction

Despite a growing interest in online support forums and patient-provider communication systems, knowledge of the relative use and benefits of these communication systems is still limited. In particular, there is little information about how patients' communications with care providers online differ from communications in discussion groups. Additionally, while a few studies have analyzed online messages between patients and physicians, online patient-nurse communication and the potential for nurses to support patients via the Internet is as of yet largely unexplored. The purpose of this study, therefore, was to compare the content of patient-nurse messages to messages posted on an online discussion forum for cancer patients. The study is part of a larger ongoing trial testing the effects of WebChoice, an internet support system for breast- and prostate cancer patients [1]. WebChoice includes tools for symptom monitoring, tailored information to support self-management, support forums for anonymous group discussion, as well as a more "private" communication area to exchange messages with a CNS specializing in cancer care.

Methods

We examined forum postings and e-mail messages by patients who logged on to WebChoice at least once from March - October 2006, resulting in a sample of 355 postings and 174 e-mails. Messages were coded according to the 'type' and 'topic' categories listed in Table 1 below. The 'type' categories are consistent with the coding schema of Klemm *et al* [2]. A message could belong to more than one category. An e-mail with questions about lymphedema and anxiety, for example, would be coded as *information seeking* for 'type', and *symptoms* and *feelings* for 'topic'. Messages were independently coded by two of the authors (AJ and TA) and 10% were coded by both to compare interrater agreement, established at 98 % for e-mail messages and 97 % for forum postings.

Results

Table 1 shows the percentages of e-mails and forum postings coded under the various 'type' and 'topic' categories.

Table 1 - Percentage of messages categorized by type and topic

		E-mails (*174 total*)	**Postings** (*355 total*)
TYPE	Personal experiences/ opinions	66	75
	Information giving	2	20
	Information seeking	62	20
	Encouragement / Support	0	17
	Thanks	22	8
TOPIC	Health personnel / institutions	21	20
	Treatment / Tests / Test results	63	59
	Symptoms / Side-effects	64	66
	Energy / Fatigue / Sleep	9	10
	Feelings	14	10
	Sexuality / Partner	3	7
	Family / Colleagues / Others	5	3
	Living with cancer / Lifestyle	22	23
	Metastasis / Relapse	7	8

The average number of topic categories per e-mail or posting was 2.4 (±1.5) and 2.3 (±1.3), respectively. As seen in Table 1, patients were concerned with largely the same topics in their e-mail messages and in their forum postings, but the type of message or posting varied, with e-mails being more 'information seeking' in nature and postings being more 'supportive' and 'information giving' to others.

There were also differences in use of the e-mail component of the WebChoice system compared to use of the discussion forum in terms of the number of participants actively using these two different components. 71% of participants given access to WebChoice logged on at least once in the data collection period (43 females and 31 males). Of these active WebChoice users, more patients used the patient-nurse communication area (n=45 or 61% of WebChoice users) compared to those submitting messages to the forum (n=34 or 46% of users). This holds true for breast cancer patients as well as prostate cancer patients. 72% of female users who logged on to the system at least once between March to October 2006 sent at least one e-mail to the nurse while 58% submitted at least one posting. 45% of active male users sent an e-mail to the nurse while 29% contributed to the forum. However, while more patients wrote e-mails to the nurse compared to the number of patients who submitted a posting in the forum, those patients actively participating in the discussion forum submitted on average more postings (10.4±10.5) compared to the average number of e-mails sent to the nurse (3.9 ± 4.6).

Discussion and conclusion

This sample of messages and forum postings, although small, provide useful information for health professionals interested in online communication systems. In a number of computer-based support systems for patients the communication areas are consistently highlighted as the most popular sections of the system, yet our knowledge about patients' use and benefits of different features within these communication areas is limited. A preliminary usage analysis of WebChoice suggest the forum is so far the most visited section in this support system [3], but the fact that more patients submit messages to the nurse via e-mail compared to the forum, and that the nature of messages in these two communication areas differ, suggest that opportunities for patient-nurse communication can provide valuable support for patients beyond that of support offered by participation in online discussion groups. Patients often experience multiple symptoms during treatment and rehabilitation, yet short hospital admissions allow little time for detecting and relieving these. Moreover, side-effects of certain treatments are often worst after the patients are discharged to home.

Therefore, patients could greatly benefit from support through an Internet based system, where they can communicate with a care provider independent of scheduled hospital or doctor appointments in an environment that is readily accessible and even anonymous. In this sample almost all of the questions patients asked via e-mail could be appropriately addressed by the CNS and did not require advice from a physician or other specialist. This suggests that online communication with a nurse may potentially reduce not only needless patient suffering and worrying but also the numbers of doctor's appointments scheduled. As cost concerns and shortages of health professionals continue to rise, online peer- and professional support provided by nurses could prove a viable health care supplement that can improve delivery of high quality patient care in the future [4].

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