Challenges of social networking technologies for cancer care and social support
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Abstract
Online communities and web-based messaging tools are valuable tools for cancer care and social support. Developers of these systems should be prepared to address the challenges of including social networking and emerging web technologies in clinical and consumer informatics systems. Experiences and challenges from a pilot test of a web-based messaging and social networking system for cancer patients will be discussed, and recommendations are offered for system design and adoption.

Introduction
Social networking sites are increasing in popularity, and provide new opportunities for social interaction. However, these tools also present new challenges for design and implementation, such as introducing new social contexts to information sharing and privacy.\(^1\) Social networking and related emerging web technologies such as blogs and wikis may improve the coordination of care and support.\(^2\) Research is needed on the challenges of providing these technologies for cancer patients and caregivers.

Methodology
A two month pilot test of a novel online communication system was conducted at a University Medical Center. The system included a buddy list, journaling, messaging, and personal profile features. An in-depth case study of a cancer survivor undergoing chemotherapy, her oncologist and clinic team, and her family and friends was used to evaluate the system design and adoption. Based on a formal survey and informal feedback by the patient, four specific challenges specifically related to social networking and web-based interface design were identified.

System Design and Adoption Challenges
1. Sending vs. Posting
The patient was not always sure which of her messages, journal entries, and profile changes were “sent” to her friends and family, and which were only “posted” for them to access. Informatics developers can provide more explicit feedback in the system design to clarify this difference to users who are used to email and directed messaging.

2. Who can see what information?
The pilot system included spaces for family and friends, the clinic team, other patients, and a private space. The patient indicated in a survey response that “I have used my private space the least. I’m still not sure who can have access to it. I write in a book journal and feel more private.” As more types of social and clinical relationships are included in a clinical or consumer information system, the participants must be better informed about potential inadvertent personal disclosures.

3. Spell Check
In a survey response, and informally throughout the pilot, the patient indicated that spell check was her most desired feature. The extent to which the lack of spell check affects the patient’s use of a web-based interface may not always be obvious to the developers. During the first week of the pilot, the patient mentioned that she read over her profile four times to check for spelling errors.

4. Inviting the social network
A major challenge during the pilot was inviting the family and friends to register on the system. Several people thought that the system-generated invite email was spam. The patient also suspected that her friends may not realize that they need to sign on to the site to read her messages.

Conclusion
These four challenges suggest that while social networking technologies have the potential to improve care and support, more research is needed to address the barriers to effective use of these systems by patients and their social networks.

References

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