Electronic Surveillance of Testicular Cancer: Understanding Patient Perspectives on Access to Electronic Medical Records

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Abstract

Purpose: To understand patient perceptions and attitudes regarding online access to testicular cancer surveillance test results, and to identify factors that may be important in maximizing referencing of electronic medical records (EMRs) by patients for these results.

Methods: In this qualitative study, seven focus groups were conducted with a total of 22 patients undergoing surveillance for testicular cancer. Transcript data were analyzed iteratively using combined manual and computerized coding by two independent coders to generate a theoretic framework grounded in the data.

Results: Practicality, meaning of information, patient-physi-

cian relationship, risk of recurrence, and role of technology were identified as interrelated factors that frame how patients regard potential surveillance technology. The influence of each factor hinged on its relationship with reassurance—the central predominant factor. Additionally, time since start of surveillance seemed to affect the relative importance of all other factors.

Conclusion: Prevailing models of technology acceptance understate the complexity of the situation of the patient user and the implications of online access to health information. Surveillance for testicular cancer seems to be a suitable context for patient access to EMR information if patient perspectives are to be understood and considered. Reassurance is the overriding element influencing attitudes.

Introduction

Electronic medical records (EMRs) have been the subject of much discussion and controversy of late. At present, EMRs refer to records maintained in hospitals and physician offices (they are sometimes called electronic health records or EHRs). These records contain information that is entered directly by the physician or through other health system interfaces. This study explores the basis for providing effective access to EMR data as a reference source for patients with early-stage testicular cancer involved in surveillance follow-up programs. This study refers to EMRs in a hypothetical sense, as an online tool for which specific attributes have yet to be defined. The main operative function, as understood by participants, was access to surveillance test results (eg, laboratory values and imaging reports) through a patient portal. This was the crux of focus group discussions. Proponents of patient use of EMRs foresee benefits such as more active roles for patients in their health care, better understanding among patients of health and illness, facilitation of communication, and enhanced patient-physician relationships. (In this context, EMRs are distinctly separate from personal health records or PHRs, which are records into which data are entered by patients and stored for patients' personal use only.) Despite these perceived benefits, widespread use of EMRs and other electronic health applications by patients has not yet occurred. This may be attributable to a combination of various factors and circumstances; however, it seems that one major shortcoming is that a fundamental understanding of what will determine successful implementation and patient acceptance and use is lacking. Many endeavors in patient access to electronic health programs have been premature, because those implementing them have failed to appreciate patient perspectives and built erroneous assumptions into systems. In attempt-

ing merely to adapt EMR systems that were created on the basis of physician perceptions and medical idiom for patient use, the mark may be missed with respect to patient needs and preferences.

Surveillance

Surveillance is a management option for patients with early-stage testicular cancer. From the standpoint of physicians, surveillance follow-up programs for patients with early-stage testicular cancer with favorable pathology require a series of regimented and frequent follow-up investigations over several years to monitor the 20% to 30% chance of recurrent disease. However, when patients embark on surveillance programs, their perspective is more complicated and multifaceted and may deviate from the assumptions of health care professionals. What surveillance means to an individual patient is variable and shaped by knowledge, understanding, attitude, relationships, and approach to life. Do individuals view themselves as patients with cancer or as survivors who are well and undergoing follow-up? Do they see the process itself as comforting or fear provoking and threatening? What aspects of the surveillance protocol do they regard as important? Do they view the entire process as a nuisance or necessity? These are complex inquiries; however, the answers and the connotations of surveillance from the perspective of patients will to a large extent govern patients' illness-related behavior and interaction with the health care system. When designing information and communication technology to be used by patients in the context of follow-up, health professionals and technicians will benefit by setting aside assumptions and seeking answers to these questions. At face value, the population undergoing surveillance for testicular cancer may be highly suitable for accessing information in EMRs through a patient portal, given their young age and the nature of surveil-

lance, which requires long-term follow-up and frequent communication. If these or other characteristics do indeed determine demand among patients for EMR access, a deep understanding of patient perspectives on surveillance is crucial to optimizing the likelihood of the usefulness and benefit of technology.

EMRs

In most cases, EMRs are used as a clinical tool embedded with medical lexicon and principles for use by practitioners. EMRs that also contain features designed to facilitate patient access have different implications as well as the potential to change traditional roles in the health care domain. Studies have demonstrated potential for modest benefit and minimal harm associated with patients accessing their health records.¹ Specifically, the potential exists for enhancement of patient-physician relationships, perhaps by bridging knowledge gaps and facilitating communication.

Although potential benefits from patient access to EMRs are perceived, there are significant limitations in the approach to design and development of these applications. The fundamental flaw in these research approaches that may hinder our understanding of acceptance, use, and benefit of patient access to EMRs is failure to adequately understand and incorporate patient perspectives. It is crucial that concepts related to patient preference are represented and included in EMRs if they are to be meaningfully accessed through portals and referenced by patients.² Despite this realization, research conducted on the basis of involving the user (ie, the patient) in the design process has been minimal.³ Qualitative studies have identified issues surrounding suboptimal effectiveness of EMR applications and attributed inadequacies to lack of fit between the system and the needs of the user.^{4,5}

It is inevitable that in most projects to provide patient access to EMRs (ie, patient portals) that are being designed from the standpoint of practitioners and technicians, assumptions—potentially erroneous—will be built into the applications. Physicians and patients have different relationships with health and illness and may have drastically different perceptions of the meaning, value, and consequences of specific online health information. It seems essential to explore patient perspectives and minimize patient-physician discordance for the successful implementation and effective use of patient-accessible EMRs.⁶ Winkelman⁷ criticizes studies for employing physician-centered design and evaluation frameworks while describing approaches as patient centered. Winkelman adds that it may be most useful to construct patient-accessible EMRs from the ground up, with preprototype design phases that reflect understanding, consideration, and incorporation of patient perspectives.

Methods

Focus group participants were selected from a clinic database of approximately 600 patients undergoing surveillance for stage I

testicular cancer at Princess Margaret Hospital (Toronto, Ontario, Canada). Patients were initially recruited by their primary physicians, and the language and means used to introduce potential participants to the nature of the study were approved by the institutional research ethics board to minimize potential for coercion.

In total, 22 survivors of testicular cancer participated in focus groups (Table 1). The mean age of focus group participants was 39.8 years, and approximately 75% of participants resided in the greater Toronto area. The location of residence was a potential although unlikely source of bias, because the proportion of patients undergoing surveillance living in Toronto was over-represented in this sample. This is largely attributable to the fact that focus groups were conducted in the early evening in downtown Toronto, making travel more difficult.

A series of seven focus groups was conducted. The size of the groups ranged from two to six participants, and the groups were all led by the same moderator. Informed consent was obtained from each participant before focus group interviews. Each focus group lasted approximately 90 minutes. A semi-structured open-ended focus group interview guide was developed on the basis of an initial review of the literature in addition to proposed research questions and objectives. Because iterative analysis took place, some aspects of the guide were altered according to emerging themes and concepts. Transcript analysis was performed by two independent investigators, and discrepancies were addressed and resolved through regular discussions and ultimate consensus.

Results

A significant pattern of patient perceptions on surveillance was identified from the data. The pattern included the following key themes, which are conceptually linked:

- Reassurance
- Practicality
- Meaning of information
- Patient-physician relationship
- Risk of cancer recurrence
- Substitutive or supplementary role of technology
- Effect of time

However, the nucleus of our findings is related to the concept of reassurance, which seemed to be a *sine qua non* for survivors of testicular cancer. All other factors were to a large extent experienced in relation to reassurance and were eclipsed by it in terms of significance. In addition, temporality (ie, the timing of the introduction to the EMR through the portal with respect to the proximity of diagnosis) also emerged as a recurrent theme that seemed to act as a dimension conditioning all other factors, their relative importance, and their association with one another. The role of technology was the only component that applied exclusively to a hypothetical online tool, whereas all other factors indirectly explained how patients regarded the traditional surveillance process itself as experienced.

Table 1. Participant Demographics and Clinical Characteristics

Demographic or Characteristic	Participants (N = 22)	
	No.	%
Age, years		
Mean	39.8	
SD	8.2	
Location of residence		
within greater Toronto	16	72.7
outside greater Toronto	6	27.3
Tumor type		
Seminoma	19	86.4
NSGCT	3	13.6
Primary physician		
Radiation oncologist	17	77.3
Urologic oncologist	2	9.1
Medical oncologist	3	13.6
Duration of surveillance, years		
< 2	8	36.4
> 2	14	63.6
Relapse during surveillance	7	31.8
Discharged from program	4	18.2

Abbreviations: SD, standard deviation; NSGCT, nonseminoma germ cell tumor.

Reassurance: The Prevailing Factor and Fundamental Issue

From the standpoint of patients, the paramount element in surveillance for testicular cancer and access to information via a patient portal was reassurance. Focus group data were replete with expressions of anxiety, fear, support, comfort, emotion, and confusion. These data set the stage for recognition of the principal role of reassurance in the surveillance process and appreciation of how all factors that affect attitudes toward potential technologic applications were mediated by their impact on reassurance. As one patient stated, the most important consideration was “knowing that everything’s okay; being comforted.”

Practicality

In focus groups, when patients speculated on potential online access to surveillance technology, they frequently referred to issues of practicality, such as waiting time, convenience, access to care, efficiency, and cost. The relative importance of practical issues varied among individuals.

One practical issue in surveillance identified in focus group discussions was the decision of whether to undergo surveillance investigations on the same day as the clinical encounter with the physician. Making separate trips to the hospital is objectively

more time consuming, less convenient, and less efficient; however, some patients viewed these as worthwhile sacrifices in practicality for the opportunity to discuss test results face to face with their physicians. This clearly has implications for remotely accessing test results via online EMRs, which may be practical but may also have variable and unpredictable effects on reassurance.

Meaning of Information to Patients Undergoing Surveillance

As patients—particularly as cancer survivors—individuals have extremely variable preferences for information when it comes to their own health and illness. Because of its sensitive nature and the visceral reactions it may evoke, information regarding personal health is a unique type of information.

Test results seemed unanimously viewed as information crucial to patients undergoing surveillance. Each individual required and desired test results in varying degrees of scale, magnitude, and detail. What dictated these varying preferences for information detail or depth seemed to be what was required of the information by an individual to provide reassurance. Even in the face of entirely normal surveillance test results, “everything is fine” may suffice for some patients, whereas reassurance may be optimized for others only with greater detail, such as specific laboratory values or a synopsis of computed tomography scan results.

Some patients felt that a computer may be an impersonal, insensitive, and inappropriate means of conveying abnormal test results. Of most concern was the lack of immediate contact with a trusted physician and the opportunity to have questions and concerns addressed promptly. In summary, the meaning of information to patients with testicular cancer in the context of surveillance is mostly explained by its capacity to affect reassurance.

Patient-Physician Relationship

One focus group participant stressed that “there’s nothing that can substitute meeting the doctor and establishing a rapport and trust.” The patient-physician relationship may have a positive or negative effect on patient reassurance. Introducing a “third-party” computer system may have variable effects on the relationship, and patient attitudes toward its use may in part be determined by how the change in dynamic indirectly affects the reassurance factor. Most patients expressed reassurance in knowing that their physicians also had access to the same EMRs and would continue to follow their progress by being kept informed.

“I guess there is an element of comfort in my surveillance program, knowing that the doctor is going to watch over you, right?” As focus group discussions unfolded, patients speculated on means to confirm and even certify physician involvement in their care through EMR access. Participants felt that knowing their physicians had reviewed the surveillance information

would instill confidence and reassurance; they believed that the reassurance of meeting with physicians in person could possibly be gained without face-to-face interactions on the condition that electronic transmissions were personalized by physicians. In other words, reassurance can be achieved as long as physicians review the results and communicate those results. This does not necessarily imply that visits with physicians are not required; rather, it indicates that similar reassurance can be achieved by accessing information through a patient portal.

Perceived Risk of Recurrence

"My understanding is that within the first couple of years, the risk is highest. So maybe after that yeah, maybe the anxiety will go down a bit." Risk of recurrence refers to the patient's perception of both the likelihood and consequences of testicular cancer recurring while the patient is undergoing surveillance. Research has demonstrated that monitoring leads to increased perceptions of risk, which in turn leads to intrusive ideation and psychologic distress.⁸

Constans⁹ demonstrated that anxiety and risk perception are related, and the relationship is bidirectional. In other words, high level of perceived risk leads to anxiety (or lack of reassurance), and higher states of anxiety lead to overestimations of risk. In our study, it was also found that proximity to a significant event is associated with both increased anxiety and perceived risk. According to accounts of focus group participants, both perceived risk of recurrence and associated psychologic distress were magnified immediately preceding surveillance visits compared with other times.

Some studies of health behavior, particularly in preventive medicine, have suggested that perceived risk is a key motivational factor in individuals.¹⁰ Other studies have found that risk perception alone is not a strong motivational factor in health behavior, but other factors such as recommendations from personal physicians, belief that behavior can alter risk, self-efficacy, and practical issues like convenience and cost are more predictive.¹¹ When focus group participants speculated about using EMRs to access surveillance test results, perceived risk of recurrence seemed to be an important factor for consideration because it was related to reassurance.

Perceived Role of Technology: Substitute or Supplement

The perceived role of EMRs was a predominant theme identified from the data, particularly the paradigm of substitution versus supplementation of conventional surveillance. In the extreme sense, substitution can be viewed as the utter replacement of conventional means of follow-up, whereas supplementation can be considered as use of EMRs without omission of any aspect of conventional surveillance. Either end of the spectrum is conceivably problematic. The thought of outright replacement of the clinical encounter by technology was disconcerting to some patients, whereas the addition of technology to an otherwise static process was deemed unnecessary and redun-

dant. As one focus group participant said, "I'm very comfortable with using a bank machine instead of a bank teller. I'm very comfortable buying stuff online instead of walking into a store, but I've been brought up that I still see a doctor or dentist face to face."

There are perceived benefits in patients being able to access test results at their convenience. The role of EMRs is flexible and may be different depending on the patient, stage of illness, and circumstances. The disinclination to replace conventional surveillance with an online resource was echoed by several participants in different focus groups and was typically attributed to a concern that reassurance would be compromised by loss of personalization of care.

Effect of Time

Attitudes and perspectives seemed to differ in a systematic way between patients who were in earlier stages of surveillance compared with those who had been undergoing surveillance for several years. In fact, patient perspectives that determine technology acceptance may be quite different at different points in time, even for the same individual. Overall, when speculating about patient portals and information access, focus group participants seemed more receptive to the idea after sufficient time since start of surveillance had elapsed. It is possible that patients perceive greater capacity for technology to provide reassurance after significant passage of time or—more likely—less capacity for technology to provide reassurance if used early in surveillance. Additionally, temporality influences patients' perceived risk of cancer recurrence and may change the extent to which they would desire a substitutive role for EMR technology. In addition, the determinants of reassurance and how reassurance is related to the aforementioned factors are influenced by temporality; although patient-physician relationships are typically fostered and developed over time, it is evident that the patient-physician relationship is particularly important to patients in the early stages of surveillance.

Conclusion

The findings from this study should be considered as an essential first step in designing and delivering patient-accessible test results via EMRs. Although it is possible that these factors do represent actual determinants of consumer-oriented technology, we are quite confident that they play a significant role in the success of such technology. Consequently, we conclude with a short list of proposed factors for consideration by researchers, practitioners, and technicians when embarking on patient-access EMR-based technology, particularly in the setting of cancer follow-up care.

- If aspects of the patient-physician relationship provide reassurance to patients, then surveillance technology should not disrupt or interfere with these aspects and ideally should enhance the patient-physician relationship. If aspects of the patient-physician relationship fail to provide reassurance, then surveillance technology may play a role in improvement or replacement of these aspects.

- Delivery of information (particularly test results) by way of an EMR application may be uniquely meaningful to patients, and as such, an individual patient's personal criteria for reassurance may dictate the timing, magnitude, detail, and sophistication of information preferred.
- Time since surveillance began (or time since diagnosis or radical treatment) may play a role in determining an individual's acceptance and use of EMR technology.
- Whether substitutive, supplementary, or both, the role of technology as intended or perceived may influence its acceptance and use.

In short, awareness of patient reassurance as the overriding and mediating factor in surveillance permits its consideration in design, development, and implementation of a technologic application for patients. It should be appreciated that EMR-based technology in the context of active cancer surveillance should add to that reassurance, or at least, it should not reduce it. Optimizing reassurance with intervention of information and communication technology (either enhancing reassurance provided by conventional surveillance or offering other patient-

perceived benefits from EMR-based resources without compromising aspects of surveillance that afford reassurance) should be realized as an objective that may maximize the likelihood of successful implementation and meaningful use.

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References

1. Ross SE, Lin CT: The effects of promoting patient access to medical records: A review. *J Am Med Inform Assoc* 10:129-138, 2003
2. Ruland CM, Bakken S: Representing patient preference-related concepts for inclusion in electronic health records. *J Biomed Inform* 34:415-422, 2001
3. Leonard KJ: The role of patients in designing health information systems: The case of applying simulation techniques to design an electronic patient record (EPR) interface. *Health Care Manag Sci* 7:275-284, 2004
4. van't Riet A, Berg M, Hiddema F, et al: Meeting patients' needs with patient information systems: Potential benefits of qualitative research methods. *Int J Med Inform* 64:1-14, 2001
5. Ralston JD, Revere D, Robins LS, et al: Patients' experience with a diabetes support programme based on an interactive electronic medical record: Qualitative study. *BMJ* 328:1159, 2004
6. Sewitch MJ, Abrahamowicz M, Dobkin PL, et al: Measuring differences between patients' and physicians' health perceptions: The patient-physician discordance scale. *J Behav Med* 26:245-264, 2003
7. Winkelman WJ: Reconciling the patient's role in the improvement of health outcomes: Medical informatics' newest frontier. *J Med Internet Res* 6:e14, 2004
8. Schwartz MD, Lerman C, Miller SM, et al: Coping disposition, perceived risk, and psychological distress among women at increased risk for ovarian cancer. *Health Psychol* 14:232-235, 1995
9. Constans JL: Worry propensity and the perception of risk. *Behav Res Ther* Jun 39:721-729, 2001
10. Rowe JL, Montgomery GH, Duberstein PR, et al: Health locus of control and perceived risk for breast cancer in healthy women. *Behav Med* 31:33-40, 2005
11. Helzlsouer KJ, Ford DE, Hayward RS, et al: Perceived risk of cancer and practice of cancer prevention behaviors among employees in an oncology center. *Prev Med* 23:302-308, 1994

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