Web-based electronic health information systems for prostate cancer patients

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Introduction: *Providing men with prostate cancer (MPC) timely access to their health records and information (HRI) can enhance their ability to understand their condition and engage in shared medical decision making with their health care provider (HCP). The Internet is a potential means of enhancing such interactions.*

Materials and methods: *Two surveys were conducted at a PC support group in Victoria, BC to identify the health information needs of MPC and the ability to access their HRI. Another objective was to identify the potential role of web-enabled HRI systems at meeting these needs. Sixty-one participants (41 men and 18 spouses/significant others (SS)) completed the first convenience survey and 16 participants then took part in a focus group meeting using a second questionnaire.*

Results: *The majority of men (median age 70 years) were knowledgeable with the computer and Internet. The majority of men (75%) desired the ability to access their HRI through means other than by meeting with their HCP, with the Internet ranking as one of the most desired methods. There was broad interest in accessing various parts of their health record and during different phases of their care. Most men were willing to try a personalized patient web-enabled HRI system. Over 70% of SS desired the ability to access their men's HRI.*

Conclusions: *The surveys indicate that the Internet is a desirable means of accessing electronic HRI and support the potential role of web-enabled HRI systems for PC patients.*

Key Words: prostate cancer, health information, electronic health records, Internet

Introduction

Medical decision making has evolved into a shared process between health care providers (HCP) and patients. Nowadays, men with prostate cancer (MPC) prefer to assume active roles with medical decision making.[1] They can be faced with difficult decision making regarding their care, often in the absence of sufficient high-level supportive medical evidence (e.g. choosing between prostatectomy, external beam radiation, brachytherapy, or cryo-ablation for localized PC). Studies have shown that PC patients exhibit high health information-seeking behavior[1-3] and that there are gaps between health information desired by PC patients and the information provided to them by their HCP.[3,4] Providing MPC timely access to health information and records (HRI) can facilitate knowledge translation and medical decision making.

A growing number of patients seek health information using the Internet.[5] The vast majority of websites provide health information that is generalized and not patient specific. Use of these

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types of websites does not necessarily translate into appropriate knowledge transfer to patients.[6] Alternatively, personalized electronic HRI systems accessed through the Internet has the potential to provide specific tailored responses to patient information needs.[7,8] These systems also allow the incorporation of electronic decision support tools to aid in decision making.

The purpose of this report is to describe the results of a series of meetings and surveys inquiring about the needs and access to HRI by MPC and their spouse/significant other (SS).

Methods

In August 2002, a convenience sample was obtained from 41 men and from 18 SS attending a regular monthly meeting at a PC patient support group called Prostate Support Association of Victoria (PSAV)[9] located in Victoria, British Columbia. Participants were asked ad hoc to complete a survey questionnaire (Q1). The main purpose of the questionnaire was to determine the information needs of men with PC and their SS and whether patient specific electronic HRI was a potentially desirable source of information.

In November 2002, a special focus group meeting was held with 11 men and 5 SS who volunteered to attend this meeting. The majority of these men attended the first meeting and completed Q1. The meeting consisted of a presentation with PowerPoint® slides followed by completion of a second questionnaire (Q2) and open discussion period. The main purpose of this meeting was to determine the information needs of men with PC in more detail. A section for SS was included in Q2 to identify their information needs. The PowerPoint® presentation introduced concepts of personal HRI for PC patients. The presentation also introduced the concept of a personalized computer-based patient HRI system and provided generic examples of PC related health records in electronic format. The presentation was created with the assistance from a local software developer (LogicLynx Technologies, Inc.).

Table 1 shows a truncated version of the information needs section of Q1. The majority of questions in both Q1 and Q2 were tick-box type responses. There was also space for written responses. Q1 consisted of the following categories of questions: patient demographics, health status, computer knowledge, health information needs, access to HRI, desired features of a personalized PC website and involvement of SS with information access. Q2 consisted of the following categories of questions: patient demographics, health status, computer knowledge, health information needs, access to HRI, desired features of a personalized PC website, and a separate section for SS to complete to identify their information needs.

Results

Participant profiles

The demographics, computer knowledge and health status of the participants from Q1 and Q2 sessions are summarized in Table 2. These surveys reflect largely the results of MPC, as $\geq$90% had a diagnosis of PC, with a median age of 70 years from Q1 and 68 years from Q2. Between 85%-91% of participants received some form of local therapy for their PC and 55%-68% received hormone therapy across the two surveys. The majority of men (80%) from Q1 knew how to use personal computers and the Internet. Sixty-one percent and 82% used the Internet as a source of health information in Q1 and Q2 respectively.

Satisfaction with health information

Table 3 shows the tabulated results regarding participants' level of satisfaction with the way their HRI was provided to them and processed. Most patients ($\geq$79%) were satisfied with HRI provided by their physicians including family doctors, urologists and oncologists. The lowest rating (44%) was associated with the news media (e.g. newspaper, television). Questions were also elicited regarding how satisfied participants were with the way their health records were managed and processed by their HCP. Fourteen to 35% were not satisfied with various aspects of their health record management or processing.

Health information needs, access and preferences

As shown in Table 4, most patients (78%) preferred to receive their personal HRI by the usual patient-doctor visit. However, 75% of men from Q1 desired the ability to access their health records through means other than by visiting their HCP. In Q1, less than 15% preferred to receive their information by mail, fax or phone call, whereas at least 30% preferred e-mail, Internet or printed material. Similar results were noted from Q2 with the exception that all 11 men preferred e-mail or Internet access to their health records. Nearly all men (95%) preferred to be directly involved with providing information to their physicians.

Regarding SS participation in HRI sharing, 68% of men were willing to allow their SS to access their

TABLE 1. **Truncated information needs section from Q1**

Information needs

What is your level of satisfaction with the medical information provided to you by:

	Not applicable	Extremely satisfied	Mostly satisfied	Mixed	Mostly dissatisfied	Extremely dissatisfied
Your family doctor	_____	_____	_____	_____	_____	_____
Your urologist	_____	_____	_____	_____	_____	_____
Your radiation oncologist	_____	_____	_____	_____	_____	_____
The Prostate support group	_____	_____	_____	_____	_____	_____
Fellow patients with prostate cancer	_____	_____	_____	_____	_____	_____
Prostate cancer websites	_____	_____	_____	_____	_____	_____
Prostate cancer chat lines	_____	_____	_____	_____	_____	_____
Prostate cancer books	_____	_____	_____	_____	_____	_____
Prostate cancer videos	_____	_____	_____	_____	_____	_____
Seminars or lectures on prostate cancer	_____	_____	_____	_____	_____	_____
Newspaper articles or television programs on prostate cancer	_____	_____	_____	_____	_____	_____

Are you satisfied with the way your personal medical information has been handled in the following manner?

	Satisfied	Mixed	Not Satisfied
Your access to your medical records and test results	_____	_____	_____
Your information remaining confidential and private	_____	_____	_____
Your information getting to your doctor in a timely fashion	_____	_____	_____
Accurate information getting to your doctor	_____	_____	_____
Accurate information provided to you	_____	_____	_____
Information was complete	_____	_____	_____
Information provided to you was clear and easy to understand	_____	_____	_____

Do you prefer to be directly involved in providing information to your doctor? _____Yes _____No

Would you feel more empowered (more in control) of your health with access to your personal medical information? _____Yes _____ No

I prefer to give my doctor the full responsibility of handling my personal medical information and providing me with the correct & necessary information. _____True _____ False

The following information can be provided to you by your doctor when you visit your doctor.
Some patients prefer to have access to this information through other means (e.g. paper copy, e-mail).
Please indicate below which information you prefer to have access to, other than by visiting with your doctor.

	I already have access to these records through other means	I would like to have access to these records through other means
Blood test results (e.g. PSA levels)	_____	_____
Imaging study results (e.g. X-ray, bone scan, CAT scan)	_____	_____
Doctor's notes	_____	_____
Pathology reports (e.g. results of prostate biopsies)	_____	_____
Medications you are taking	_____	_____
Treatments you have received for your cancer	_____	_____
Experimental treatments or studies you are eligible for	_____	_____
Other patients experience with prostate cancer	_____	_____
Other (please list):	_____	_____

TABLE 2. **Truncated results of Q1 and Q2: profile of men**

	Q1 (n=41)	Q2 (n=11)
Demographics		
Median age (range)	70 years (48-87)	68 years (62-76)
	Percent %	
Highest level of education		
Secondary or lower	47	0
Post-secondary	43	82
Not specified	10	18
Ethnicity		
Caucasian	97	100
Other	3	
Health Status		
Diagnosed with PC	90	91
Type of treatment received:		
Watchful waiting (i.e. No treatment)	4	18
Local (e.g. prostatectomy, prostate brachytherapy, external beam)	85	91
Hormone therapy	68	55
Chemotherapy	0	0
Computer/Internet knowledge & access		
Able to use computer	80	100
Used computer at home	71	100
Type of internet access:		
Modem	44	
High speed access	56	
Used internet	76	82
Used e-mail	71	100
$\geq$ 5 hours per week of home computer use	NA	82

NA = Not asked

personal health information and records and 72% of the SS desired the ability to access their men's records.

Personalized PC patient website

Table 5 summarizes the questions regarding the potential role of a web-enabled HRI system for PC patients. The majority (80%) were willing to try this type of application. Patients desired obtaining information on all aspects of their medical record and in different phases of their PC care from diagnosis, treatment, follow-up, to disease recurrence. A wide range of website features was desired by men.

Sixty-four percent of men from Q1 (and 91% from Q2) preferred to use this type of application at home, whereas less than 10% would use this at a medical facility. Forty-five percent of men from Q2 would use this application while traveling abroad.

There were 36% and 55% of men from Q1 and Q2 respectively who had concerns about using this type of application with concerns regarding accuracy, security and confidentiality of information. Less than 20% of men were concerned that this type of application would be too difficult to learn and use.

Discussion

A distinction should be drawn between general health information on PC, which is widely available in printed and electronic formats, versus patient-specific HRI. There are four key findings from this study: (a) MPC are increasingly Internet savvy and desire access to HRI; (b) MPC desire electronic HRI access and sharing with their SS; (c) further research is needed on meaningful electronic HRI formats; (d) there is growing interest in electronic HRI that should be addressed. Last, limitations of this study are described.

TABLE 3. **Truncated results of Q1: men's satisfaction with health information**

	Percent %			
Level of satisfaction with health information provided by:	Satisfied	Mixed	Not satisfied	% of men using info source
Family physican	79	18	3	NA
Urologist	87	10	3	NA
Radiation Oncologist	96	4	0	NA
Prostate Support Group	95	5	0	NA
Other patients	76	24	0	NA
Lectures	92	5	3	NA
Computer/Internet	70	30	0	61
Chat Lines	27	45	18	29
Books	74	17	9	92
Videos	79	18	3	76
Newspaper or TV	44	44	12	84
Level of satisfaction with following way personal health information has been managed by HCP:	Satisfied	Mixed	Not satisfied	
Providing access to health records & test results	76	16	8	
Records remaining confidential and private	86	11	3	
Accurate information	84	13	3	
Records complete	84	11	5	
Information provided in a clear and easy to understand manner	65	30	5	
Records getting to your doctor in a timely fashion	72	25	3	
Accurate information getting to your doctor	78	22	0	

NA = Not asked

MPC are increasingly Internet savvy and desire access to HRI

A somewhat surprisingly high proportion of men with a median age of 70 years from this study were computer and Internet knowledgeable. The majority with Internet at home had highspeed access as well. These men desired access to their HRI by means other than visiting their HCP. In particular, electronic access was desirable as was noted in 34% of the responses from Q1, whereas other more traditional means ranked somewhat lower (e.g. 12% for letter, 7% for phone call, 5% for fax). This result contrasts that of Wong et al who administered a questionnaire to 100 MPC from the greater Toronto area which included questions regarding their health information format preferences.[1] The preferences in decreasing order were: broadcast media, video, telephone information lines, audiotapes and finally computers. However, only 51% of MPC had computer access compared to 71% and 100% from Q1 and Q2 respectively in this study. This indicates there is still a role of presenting HRI in traditional formats to MPC.

However, our study supports the need to investigate other means of access such as the Internet as several studies have demonstrated that the information needs of PC are not being adequately met by traditional means. For example, Fagerlin et al performed an extensive review of current publicly available PC educational material and concluded that this material did not contain sufficient comprehensive information to properly assist MPC and HCP in making informed treatment decisions.[10] They stressed the importance of finding more innovative methods of providing PC information. Snow et al identified significant information gaps (i.e. a difference in information need versus whether it was being met) in MPC along several domains ranging from treatment decisions, risks and benefits and details of treatment.[4] Likewise, Templeton et al observed significant information gaps in MPC receiving hormone therapy.[3]

TABLE 4. **Truncated results of Q1 & Q2: health information needs, access and preferences**

	Q1 (n=41)	Q2 (n=11)	
	Percent %		
Preferred means to send/receive personal health records to/from HCP:	Receive	Receive	Send
Doctor-patient encounter	78	64	64
Electronic messaging	34	100	100
Fax	5	18	27
Letter	12	18	18
Phone Call	7	9	18
Digital recorded message on computer	NA	9	9
Printed material	32		
Preferred to receive personal health records by methods other than visiting HCP	75		
Preferred to give HCP full responsibility of managing records	38		
Preferred to be involved in providing information to HCP	95		
Felt more empowered with access to own information	93		
Reasons for having access to medical info:			
No reason to access medical information	12		
To make more informed decisions regarding treatment	68		
To learn more about prostate cancer condition	68		
To learn about prognosis (expected outcome) and quality of life expectations	68		
To follow progress	66		
To communicate more effectively with cancer doctors	63		
To communicate more effectively with other doctors (e.g. family doctor)	66		
To communicate more effectively with spouse/significant other	51		
To communicate more effectively with family or friends	41		
Willingness to share personal info in anonomyzed form with:			
Unwilling to share	18		
Other prostate cancer patients	73		
Family doctor	80		
Urologist	80		
Radiation oncologist	75		
Researchers	83		
General Public	15		
Government decision makers	23		
Pharmaceutical companies	18		
Spouse/partner (SS) access to health information and records:			
Willingness to give access to SS	84		
Willingness to allow SS to enter data	68		
SS desire to access records and info	72		

NA = Not asked

MPC desires electronic HRI access and sharing with their SS

It was evident from this study that MPC desired HRI on all aspects of the medical record and during various phases of care. These results are comparable to those from Templeton et al in MPC on hormone therapy.[3]

TABLE 5. **Truncated results of Q1 and Q2: PC patient web access to their electronic health records**

	Q1 (n=41)	Q2 (n=11)
	Percent %	
Physical location where participant would use website:		
Would not use this website.	21	0
Home	64	91
Work	8	36
PC support centre	10	18
Physician's office	8	27-55
Library	8	9
While traveling, away from home	NA	45
Concerns about website:	36	55
Too difficult to use	14	18
Security	79	27
Confidentiality	64	36
Inaccurate information	43	55
Missing information	50	36
Misuse of information by persons managing or accessing website	43	36
Information getting lost or misplaced	50	36
Data entry accuracy	7	
Proper consent obtained		18
Phase of medical care that patient would use website:		
Never	15	0
Before a diagnosis of PC is made (e.g. screening)	18	36
During work-up of PC, before cancer treatment is given	54	82
During cancer treatment decision making process	67	82
During actual treatment of your cancer	41	100
During follow-up	49	100
At time of cancer recurrence	46	82
Desired features or functions:		
Provide general info on PC	68	82
Provide glossary of terms used in PC	57	0
Provide general treatment options for PC	73	82
Provide list of available treatments or experimental studies	49	73
Provide list of PC specialists in region	49	73
Provide list of pharmaceutical companies that provide medications for PC	11	55
Provide links to other PC websites	57	91
Provide customized advice or health information based on patient specific profile:	51	100
Treatment options	84	100
Prognosis	95	100
Risks and potential complications from treatment	100	100
Experimental studies or clinical trials	NA	91
Email messaging to PC doctors	35	91

TABLE 5. **Truncated results of Q1 and Q2: PC patient web access to their electronic health records (cont)**

Email messaging to family doctor	22	91
Email messaging to other PC patients	3	55
Chat Lines with other patients	3	73
Share other PC patients experience	NA	82
Management of treatment complications	3	NA
List of PC medical journals and current research	3	NA
Nutrition counseling	NA	91
Alternative/complementary therapies for PC	NA	55
Type of personal electronic health records participants wanted access to:	NA	
Blood test results		100
Summary of treatments received		100
Pathology reports		91
Appointments for doctor visits and tests		82
Imaging study results		73
Actual images of x-rays, bone scans, CAT scans		45
Doctor's notes		73
Medical conference notes		45
Operative notes		73
Special procedure notes		73
Current medications		73
Medications taken previously		73
Allergies to medications		82
Preferred format of electronic health records that patients preferred to view	NA	
F1 = Full report and images		63
F2 = Report summary		63
F3 = Revised summary suitable for layperson viewing		73
Would agree to view in F1 or F2 if F3 format was not available		100

NA = Not asked

In that study, participants desired information mostly on treatment details, types of treatment, tests, PC and diagnosis. These men were offered education sessions and over 50% preferred the outpatient setting, including 20% with a preference at home. Although the proposed information intervention was different in that study (i.e. education session), it emphasizes the desire for MPC to receive information closer to home. This is consistent with results from this study that indicated that most men preferred to use an electronic HRI system at home. Interestingly, 45% of men surveyed in Q2 thought the application would be useful while traveling away from home. The Internet is well suited for this type of remote access at home and abroad.

In our survey, there was a series of questions pertaining to patients' willingness to share their personal health records for research or statistical purposes as long as it was anonymized. One example of such an existing research database is Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE^{TM}) which is a longitudinal observational study of PC patients in the USA.[11] The minority (18%) in this survey would refuse to share their information and this suggests that sharing of anonymized personal health information was not a major concern from MPC as long as the intent and usage of this information was purposeful and explicit. The protection of privacy and security of patient electronic information was not cited as a major concern, but is gaining awareness mainly amongst the stewards of patient data. There has been progress addressing these concerns through legislative and regulatory measures.[12] Interestingly, the majority of men (>75%) were not willing to share their information with the government, public and pharmaceutical companies. This raises the question of why men with PC would not entrust their information with public and private sectors.

This study also supports SS interest and access to HRI as the majority of men were willing to share their HRI with their SS. Likewise, the majority of SS desired access to various aspects of HRI. Previous research has shown that SS of MPC may ask more questions than their men.[13] Talcott et al found that the participation of wives was a factor in treatment decision making in a survey of 560 men with localized PC.[14] Thus, the impact and role of SS should not be trivialized.[13,15,16] The Internet may represent a means of also addressing the information needs of SS.

Further research needed on meaningful electronic HRI formats

The preferred format and display of patient electronic health records has not been well studied. An attempt to elucidate the preferred format was made in Q2 and results shown at the bottom of Table 4. Participants were given three formats to view their electronic health records. Format one (F1) consisted of the actual report and images that would be normally viewed by their HCP. Format two (F2) consisted of only the summary or truncated report and format three (F3) was a modified summary version suitable for patient or layperson viewing. There was no strong preference for any format. What was most notable was that all men in Q2 would be willing to view their personal health records if it were not available in F3. Translating health records into a form that is more easily interpreted by patients (i.e. F3) is a more labor-intensive task and cannot be easily automated with current technology. Another interesting observation was that 45% of men from Q2 desired the ability to view the actual diagnostic images if it were available to them electronically. However, incorporating radiologic images requires more intensive computer memory and processing power.

There is growing interest in electronic HRI that should be addressed

Patient health records are increasingly available for use in electronic form to HCP. At present, electronic health records (EHR) are not readily accessible to patients in Canada. There is increasingly more peer-reviewed literature regarding patient-oriented websites devoted to self-care in such conditions as diabetes mellitus,[17,18] cancer,[19,20] breast cancer,[21] HIV,[22] gyneocology.[23] For example, Jones et al randomized 525 cancer patients receiving radiotherapy to three groups consisting of health information provided by booklets, general information provided by computer, and personalized information including health records by computer.[24] This study concluded that there were certain benefits to providing patient HRI electronically and that this was cost effective over time. In France, a study of 150 MPC treated with radical prostatectomy who had Internet access to their health records demonstrated that over 90% of subjects consulted the website on a regular basis and were satisfied with the website.[25] Technical or connection problems occurred in <15% of men. The application permitted the patients to view and track their personal treatment and medical reports, blood tests results (such as prostate specific antigen), digital video clips and instructional material over the Internet in a secure manner. This system was a regarded as an innovative and complementary means of follow-up care for PC patients having completed prostatectomy.

In Canada, there is growing interest for web-based patient HRI systems. The centre for Global eHealth Innovation from Toronto has launched the Internet clinical communication centre project or iC3 that examines how PC patients communicate with the HCP and manage their health through access to their interactive web-based EHR.[26] My CARE Source[27] is a computer-based tool for patients to track their status during treatment and provides a personalized plan for their care. In 2004, a workshop on PC Informatics and the Internet was held in Toronto, Ontario to help identify informatics initiatives and solutions for PC care and research. One of the breakout sessions was devoted to the subject of patient access to personal HRI. There was a general consensus that there is a need for more evidence-based literature supporting Internet-based applications for PC patient access to their HRI.

This study is limited by small sample size, particularly in Q2, the use of a non-validated convenience questionnaire and the demographic profile of participants who were predominately of English speaking Caucasian background living on Vancouver Island and in Q2, well educated. The age distribution was reflective of MPC and treatment received was well distributed except for an absence of MPC receiving cytotoxic chemotherapy. It should also be noted that 61% of men from Q1 completed the survey while they were in the follow-up phase of their PC care. Response to survey questions may be influenced by the disease trajectory and the cumulative experiences associated with each phase of care. The surveys were conducted through a local PC support group and it is acknowledged that cancer patients attending support groups likely represent a subset of patients who tend to be high information seekers and not representative of the general population of oncology patients. Therefore, this study does not address the general applicability of web-enabled HRI systems for all MPC. As well, volunteer bias from Q2 may limit generalizability compared to Q1.

Conclusions

PC is a common, chronic-behaving disease where self-management and shared medical decision making are essential components of patient care. Men with PC exhibit high information seeking behavior. Previous research has identified gaps in providing useful information by traditional means. Although there is an abundance of general PC-related health information, timely access to personalized HRI is a more tailored approach at meeting information needs. The results of these surveys, albeit in a selected group of PC patients who tend to be high information seekers and computer knowledgeable, indicate that MPC had the desire to access their HRI using electronic means. The majority of SS had the desire to participate in the care of their MPC by accessing their HRI. This study supports the investigation and development of web-enabled access to personal electronic HRI as a means to meet the information needs of MPC and their SS.[28, 29] ☐

References

1. Wong F, Stewart D, Dancey J et al. Men with prostate cancer: influence of psychological factors on informational needs and decision making. *J Psychosomatic Research* 2000;49:13-19.
2. Davison BJ, Degner LF, Morgan TR. Information and decision-making preferences of men with prostate cancer. *Oncol Nurs Forum* 1995;22(9):1401-1408.
3. Templeton HRM, Coates VE. Informational needs of men with prostate cancer on hormonal manipulation therapy. *Patient Education and Counseling* 2003;49:243-256.
4. Snow SL, Panton RL, Butler LJ, Wilke DR, Bell DG, Rendon RA. Identification of an information gap for informed consent in early stage prostate cancer (PCA). Proceedings from Canadian Urological Association, 59th Annual Meeting, Whistler, Canada. *The Canadian Journal of Urology* 2004;11:2266(abstract 150).
5. Ethics survey of consumer attitudes about health web sites. *National Press Club* 2000 (Accessed at http://www.chcf.org/documents/consumer/surveyslides.pdf).
6. Benigeri M, Pluye P. Shortcomings of health information on the Internet. *Health Promot Int* 2003;18(4)):381-386.
7. Gustafson DH, Bosworth K, Chewning B, Hawkins RP. Computer-based health promotion: combining technological advances with problem-solving techniques to effect successful health behavior changes. *Annu Rev Public Health* 1987;8:387-415.
8. Nyhof-Young J, Catton P. Promoting effective clinical practice: Patient education and oncology care. Oncology Rounds from Princess Margaret Hospital 2003;5(1).
9. Prostate Cancer Association of Victoria. (Accessed at http://victoria.tc.ca/Community/MensCentre/prostate_cancer.html).
10. Fagerlin A, Rovner D, Stableford S, Jentoft C, Wei JT, Holmes-Ravner M. Patient education materials about treatment of early-stage prostate cancer: A criticial review. *Annals of Internal Medicine* 2004;140(9):721-728.
11. Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE ™). (Accessed at http://www.capsure.net/overview.htm).
12. Canadian Standards Association's Model Code for the Protection of Personal Information. (Accessed at http://www.csa.ca/standards/privacy/code/Default.asp?language=english).
13. Riechers E. Including partners into the diagnosis of prostate cancer: a review of the literature to provide a model of care. *Urol Nurs* 2004;24(1):22-29, 38.
14. Talcott JA, Crystal B, Manola J, Clark JA, Mitchell SP. Choosing treatment for early prostate cancer: Factors predicting treatment modality and satisfaction. In: Grunberg SM, editor. 2005 Multidisciplinary Prostate Cancer Symposium; 2005 Feb 17-19, 2005; Orlando, FL: American Society of Clinical Oncology; 2005.
15. Feltwell A, Rees C. The information-seeking behaviours of partners of men with prostate cancer: a qualitative pilot study. *Patient Educ Couns* 2004;54(2):179-185.
16. Srirangam S, Pearson E, Grose C, Brown S, Collins G, O'Reilly P. Partner's influence on patient preference for treatment in early prostate cancer. *BJU Int* 2003;92(4):365-369.
17. Kwon H, Cho J, Kim H et al. Development of web-based diabetic patient management system using short message service (SMS). *Diabetes Res Clin Pract* 2004;66(Suppl 1):S133-137.
18. Ralston J, Revere D, Robins L, Goldberg H. Patients' experience with a diabetes support programme based on an interactive electronic medical record: qualitative study. *BMJ* 2004;328(7449):1159.
19. Cimino J, Patel V, Kushniruk A. The patient clinical information system (PatCIS): technical solutions for and experience with giving patients access to their electronic medical records. Int J Medical Informatics. 2002;68(1-3):113-27.
20. Ruland C, Andersen R. Designing WEB-CHOICE - Individualized Support for Cancer Patients through the Internet. In: Medinfo; 2004:1840.
21. Gustafson D, Wise M, McTavish F et al. Development and pilot evaluation of a computer-based support system for women with breast cancer. *J Psychosocial Oncology* 1993;11(4):69-93.
22. Gustafson D, al e. Impact of a patient-centered, computer-based health information/support system. *Yearbook of Medical Informatics* 2001:224-232.
23. Baorto D, Cimino J. An "infobutton" for enabling patients to interpret on-line Pap smear reports. In: Proceedings of American Medical Informatics Association Annual Symposium 2000:47-50.
24. Jones R, Pearson J, McGregor S et al. Randomised trial of personalized computer based information for cancer patients. *Yearbook of Medical Informatics* 2001:233-239.
25. Cathala N, Brillat F, Mombet A et al. Patient followup after radical prostatectomy by Internet medical file. *J Urol* 2003;170(6, part 1):2284-2287.
26. The Internet clinical communication centre project (iC3): Examining the clinical encounter in the information age. (Accessed at http://www.oci.utoronto.ca/ehealth/html/what/eh_what_projects_ic3.shtml).
27. My Care Source. (Accessed at http:/www.grandriverhospital.on.ca/pdf CARESource.pdf).
28. Forkner-Dunn J. Internet-based patient self-care: the next generation of health care delivery. *J Med Internet Res* 2003;5(2):e8.
29. Eysenbach G, Jadad A. Evidence-based Patient Choice and Consumer Health Informatics in the Internet Age. *Journal of Medical Internet Research* 2001;3(2):e19.