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Original Paper

Can Clinical Trials Requiring Frequent Participant Contact Be Conducted Over the Internet? Results From an Online Randomized Controlled Trial Evaluating a Topical Ointment for Herpes Labialis

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Abstract

Background: The Internet has tremendous appeal for conducting randomized clinical trials and may be especially applicable to trials requiring frequent participant contact. Trials of cold sore remedies, for example, often require daily clinic visits during outbreaks, imposing substantial burden on participants. An Internet-based randomized clinical trial design may reduce this burden, permitting frequent symptom reports with considerably less effort.

Objective: To evaluate the feasibility of a Web-based randomized clinical trial requiring frequent participant interaction, using a 6-month, double-blind, randomized, placebo-controlled pilot trial of a topical ointment containing dioctyl sodium sulfosuccinate (DSS) (Zilex; Meditech Pharmaceuticals, Inc, Scottsdale, Arizona, USA) intended for treatment of recurrent herpes labialis. A secondary objective was to obtain preliminary data on effectiveness outcomes, to assist in planning a fully-powered trial of DSS.

Methods: Adults with physician-confirmed herpes labialis were recruited to apply to the trial. Eligible applicants were randomized to DSS or placebo, mailed to them upon enrolment with instructions to apply topically every 2 hours for the duration of every cold sore outbreak. Participants were instructed to complete online questionnaires at 2-week intervals and, at the initiation of a cold sore, daily "outbreak questionnaires" until outbreak termination. Feasibility outcome measures included trial participant characteristics, frequency of cold sores, participant retention and adherence (to study medication), and data completeness. Treatment effectiveness outcome measures included outbreak duration, days to crust formation, and pain.

Results: Of the 292 individuals applying, 182 screened eligible; 32 participants with confirmed herpes labialis enrolled in the trial. 16 were randomized into the verum group and 16 into the placebo group. 29 (91%) participants completed the trial. During the trial, 34 outbreaks were reported among 23 (72%) participants, resulting in a cold sore incidence rate of 19.8 per 100 person-months of observation. Online data were available for 32 outbreaks; the absence of a resolution date made it impossible to accurately calculate the duration of 12 (38%) outbreaks. Although the DSS treatment group had a shorter mean outbreak duration (6.6 vs 7.7 days, $P= .2$) and fewer mean days to crust formation (3.5 vs 4.9, $P= .1$), these differences did not reach statistical significance. The DSS group has statistically significant lower mean pain scores (3.1 vs 7.6, $P= .04$), but participants in this group also consumed more acetaminophen tablets than the placebo group (1.1 versus 0.5, $P=.55$). Adherence to medication was similar in both groups: 7 (50%) of the verum group reported using the cream as directed compared to 6 (46.2%) in the placebo group; ($P= .8$).

Conclusions: We efficiently recruited participants and achieved high overall retention rates. However, participant adherence to the daily outbreak visit schedules was low and only 7 (50%) participants used the cream as directed. These limitations could be addressed in future Internet-based studies by using Personal Digital Assistants (PDAs), using reminder devices, and providing

incentives. By enhancing participant adherence, clinical trials requiring frequent participant contact may be feasible over the Internet.

KEYWORDS

Internet; randomized controlled trial; clinical trial; herpes labialis; dioctyl sodium sulfosuccinate

Introduction

Due to its access to vast segments of the population and its technological capabilities, the Internet has tremendous appeal as a vehicle for conducting randomized controlled clinical trials (RCTs) [1- 4]. In previous work we found it highly feasible to rapidly recruit individuals over the Internet into an online randomized controlled clinical trial of glucosamine for knee osteoarthritis [5]. The Internet-based approach may be especially applicable to randomized controlled clinical trial designs that require frequent participant contact. Trials of cold sore remedies, for example, often require daily clinic visits during outbreaks, imposing substantial burden on participants [6]. While clinic visits may represent the ideal patient evaluation, these frequent visits may hinder participant recruitment and retention. An Internet-based randomized controlled clinical trial design could theoretically reduce this burden and permit frequent symptom reports with considerably less effort.

The objectives of our study were to evaluate the feasibility of an Internet-based approach for testing a topical ointment containing dioctyl sodium sulfosuccinate (DSS) (Zilex; Meditech Pharmaceuticals, Inc, Scottsdale, Arizona, USA) for herpes labialis (oral herpes simplex, cold sores), and to collect preliminary outcome data for this potential cold sore remedy. DSS has been shown to have in vitro efficacy against herpes simplex virus type 1 through disruptive effects on the viral capsule [7]. In addition, Zilex contains benzocaine, a well-known anesthetic that has been shown to be effective in pain reduction [8,9].

Methods

Web Site Development

The study Web site was constructed on an independent server within the Boston University School of Medicine domain. The Web pages were written in Hypertext Markup Language (HTML), Active Server Pages (ASP), JavaScript, and Component Object Modeling interfaced with a Structured Query Language (SQL) Server database. Microsoft Access [10] software was used to query the database and to create reports. The security of our site was protected by a firewall and 128-bit secure socket layering encryption. In addition, we operated data-security protocols that included automated error checking, limited password-protected access to the data interface and database, permission levels, username-linked logging of all changes made in the database, participant tracking by ID number, encryption of randomization codes, and screen time-outs.

The public area of the Web site described the study and solicited participants, with hypertext links to a consent form and an eligibility-screening page. The password-protected private area of the Web site included pages where participants could view utilities and access the study questionnaires. The Web site included a batching utility that (1) sent e-mails to participants reminding them of their scheduled online "visits" and (2) included code that presented the appropriate questionnaires to each participant when logging into the Web site at the time of these visits.

Design of the Randomized Controlled Clinical Trial

This was a 6-month randomized, placebo-controlled trial of a topical ointment in the treatment of herpes labialis. The objective was to enroll 30 participants with a history of herpes labialis, randomize them to verum (Zilex) or placebo, and follow them for cold sore outbreaks. Because of the 6-month follow-up period, participants had the opportunity to report several cold sore outbreaks and the key emphasis of the trial was on the "outbreak." The primary outcome measure was duration of outbreak, which was ascertained through daily outbreak questionnaires. This study was approved by the Institutional Review Board at Boston University School of Medicine.

Recruitment and Eligibility

Adults with a history of herpes labialis were recruited through newspaper and e-zine advertisements directing them to the trial Web site, which described the study and contained an eligibility questionnaire. Eligible applicants had to be at least 18 years of age, take no immunosuppressives, report at least 4 cold sore outbreaks per year for more than 1 year, report a last-outbreak occurrence ≤ 6 months ago, and report at least moderately-severe external cold sores. Applicants who screened eligible were asked to print, sign, and mail an informed consent form including a medical-records release. When medical records could not be obtained, the participant was contacted by a physician (TM) to confirm the diagnosis of herpes labialis. The identity of all participants was authenticated by receipt of a signed consent form. In addition, authentication of participant's identities was confirmed by receipt of medical records, or by telephone.

Randomization, Medication Delivery, and Medication Application

Eligible authenticated applicants who completed a 2-week run-in phase were randomized in a double-blind manner to either verum or placebo. Staff uninvolved with other aspects of the trial maintained the computer-generated randomization list and labeled the tubes of study medication. The tubes, distinguishable only by a code number on the label, were then provided to study staff. Tubes of study medication, along with an instruction guide, were sent to participants by 2-day mail. Participants were sent an e-mail notifying them that the study medication was en route and should arrive within 5 days. Participants were asked to notify us via the study Web site when they received the study

medication. Participants were instructed to apply the study medication at the first sensation of a cold sore outbreak and continue to apply the medication every 2 hours until the cold sore healed completely.

Questionnaires

Participants were asked to complete scheduled online questionnaires at 2-week intervals; these questionnaires included information on the participant's cold sore history and remaining study medication.

Figure 1. Standard Pictorial Illustration of Cold Sore Stages as Part of the Online Outbreak Questionnaire
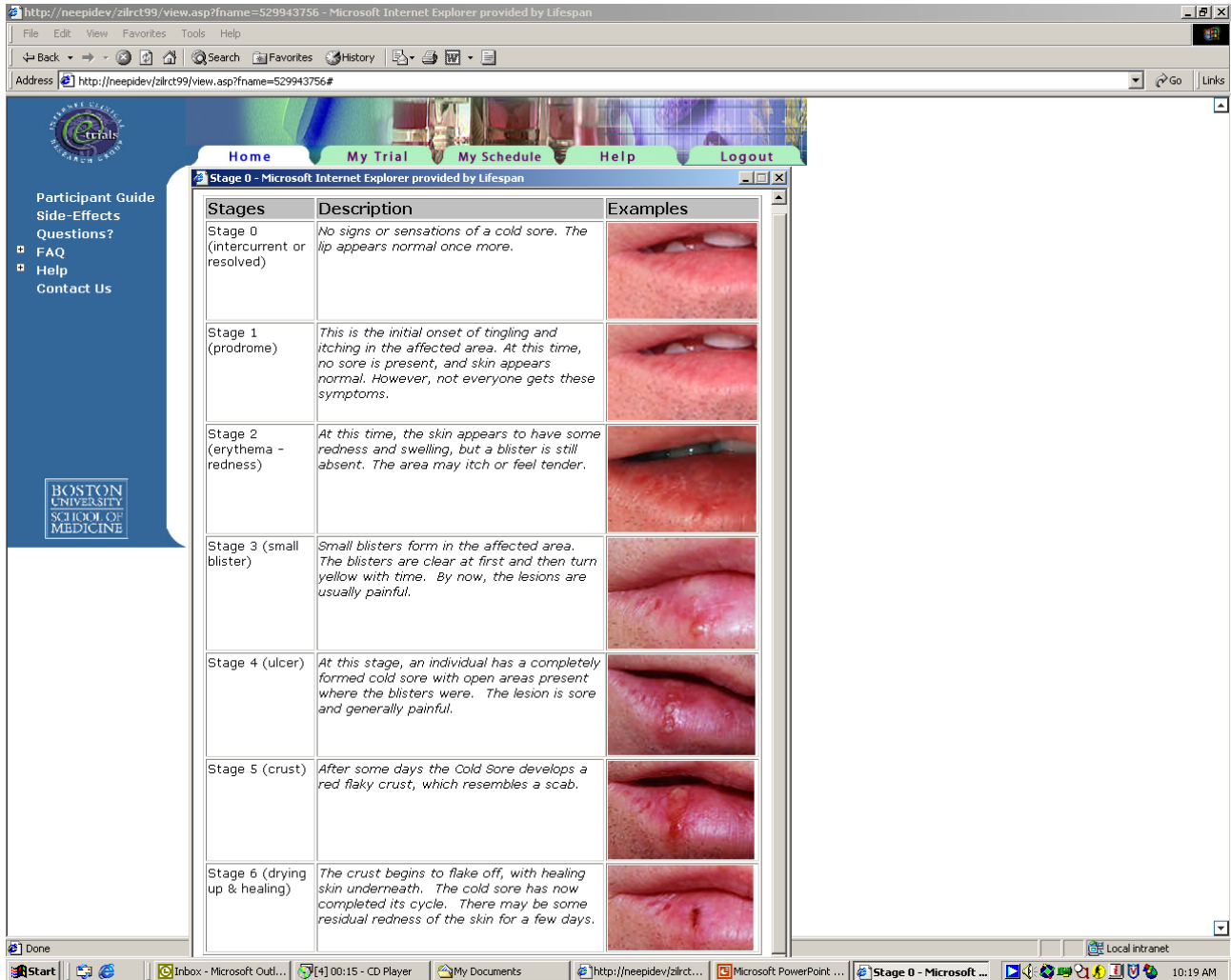
Figure 2. Part of the Outbreak Questionnaire (see also Multimedia Appendix)

At the initiation of an outbreak, participants were asked to complete daily online outbreak questionnaires, which were date stamped and included a standard pictorial illustration of cold sore evolution (stages 1-6, and 0 indicating a completely-healed cold sore; Figure 1), as well as questions on the number of clusters present, the location of the cold sore, use of pain medication or other cold sore medications, and the degree of pain associated with the cold sore (Likert scale 0-4) (see Figure 2 and Multimedia Appendix). E-mail reminders were sent to participants if they did not complete a daily outbreak questionnaire during the course of an outbreak. A supplemental questionnaire was e-mailed to participants at the completion of a cold sore outbreak; this questionnaire asked about the length of the outbreak, how long ago the outbreak occurred, adherence to study medication, and satisfaction with the study medication.

Outcome Measures

Outcome measures pertaining to the evaluation of the feasibility of conducting the trial online are descriptive in nature and include characteristics of the trial participants, frequency of cold sore outbreaks, participant retention and adherence to the study medication, and completeness of data.

Treatment-effectiveness measures included total duration of outbreak, days to crust formation, and pain. Total duration of outbreak was defined by subtracting the date of the initial online outbreak questionnaire from the date of the outbreak questionnaire that indicated the cold sore had healed completely. Days to crust formation was defined by subtracting the date of the initial online outbreak questionnaire from the date of the online questionnaire in which the participant first reported that the cold sore had reached at least stage 5. Pain was defined as the sum of the daily pain scores for the duration of the outbreak. Additional outcome measures included sum of the daily scores for cold sore stage, sum of the number of clusters reported daily for the duration of the outbreak, and the sum of acetaminophen tablets taken over the duration of the outbreak.

Adverse Events

Participants were asked to report any adverse events via a form on the Web site, e-mail to the study staff, or a toll-free telephone line. The daily online outbreak visit questionnaire also allowed participants to report comments on the feel, taste, or performance of the study cream. In addition, participants were asked in the supplemental e-mailed questionnaire if they had any problems with the study cream.

Statistical Analysis

We used an intention-to-treat analytic approach. In cases where the total duration of an outbreak could not be calculated because the endpoint of the outbreak was unclear or the participant

informed us of the outbreak only after it occurred (N = 2), we imputed a duration based on the mean duration of all of the other outbreaks. This method was used for the days to crust formation, sum of the daily pain scores, sum of the daily stage scores, sum of the number of clusters reported daily, and sum of acetaminophen tablets taken over the duration of the outbreak. Additional analyses were conducted excluding outbreaks for which imputation was necessary.

Baseline characteristics of the treatment groups were compared using Fisher exact tests and t tests. Differences between the treatment groups were evaluated using Wilcoxon rank sum tests for continuous outcome measures and Fisher exact tests and chi-square tests for categorical outcome measures. Generalized linear models were used to test for differences after adjusting for gender and age.

Results

Figure 3 shows the CONSORT flow diagram [11] of the trial from application to completion. Of the 292 individuals who applied to the trial, 182 screened eligible, and 40 mailed signed consent forms. Ultimately, 32 participants with confirmed herpes labialis completed the 2-week run-in phase and enrolled in the trial, verum (N = 16) or placebo (N = 16).

The mean age of participants was 43 (range, 20-72). 23 (72%) were female and all participants were Caucasian. Baseline characteristics of the participants by randomized group are displayed in Table 1. The groups were similar with respect to geographic region, but differed with respect to age and gender,

although these differences did not reach statistical significance on a 5% level.

Three participants were lost to follow-up, resulting in 29 (91%) who completed the trial. During the course of the trial, 34 outbreaks were reported among 23 (72%) participants. After accounting for losses to follow-up, the cold sore incidence rate was 19.8 per 100 person-months of observation. Two outbreaks occurred while participants were on vacation, leaving 32 outbreaks for which online data were available.

Figure 4 illustrates the completeness of data, as well as self-reported stage for the 32 cold sore outbreaks for which we had online data. Due to missing data at the end of the outbreak, total duration of outbreak could not be calculated for 12 (38%) and days to crust formation could not be calculated for 10 (31%) of the outbreaks. The stages for 14 (44%) outbreaks followed a normal cold sore evolution.

Results adjusted for gender and age did not differ substantially from unadjusted results, therefore, only the former are presented. The verum group had a shorter mean duration of outbreak, fewer mean days to crust formation, and lower mean sum of clusters than the placebo group, but none of these differences reached statistical significance. The verum group had a statistically significant (P=.04) lower mean sum of daily pain scores than the placebo group (Table 2). The mean sum of acetaminophen tablets taken over the course of the outbreak was slightly higher in the verum group compared to the placebo group. Analyses that excluded outbreaks for which imputation was necessary had similar results, but the magnitude of difference between the treatment groups was greater.

Figure 3. CONSORT flow diagram
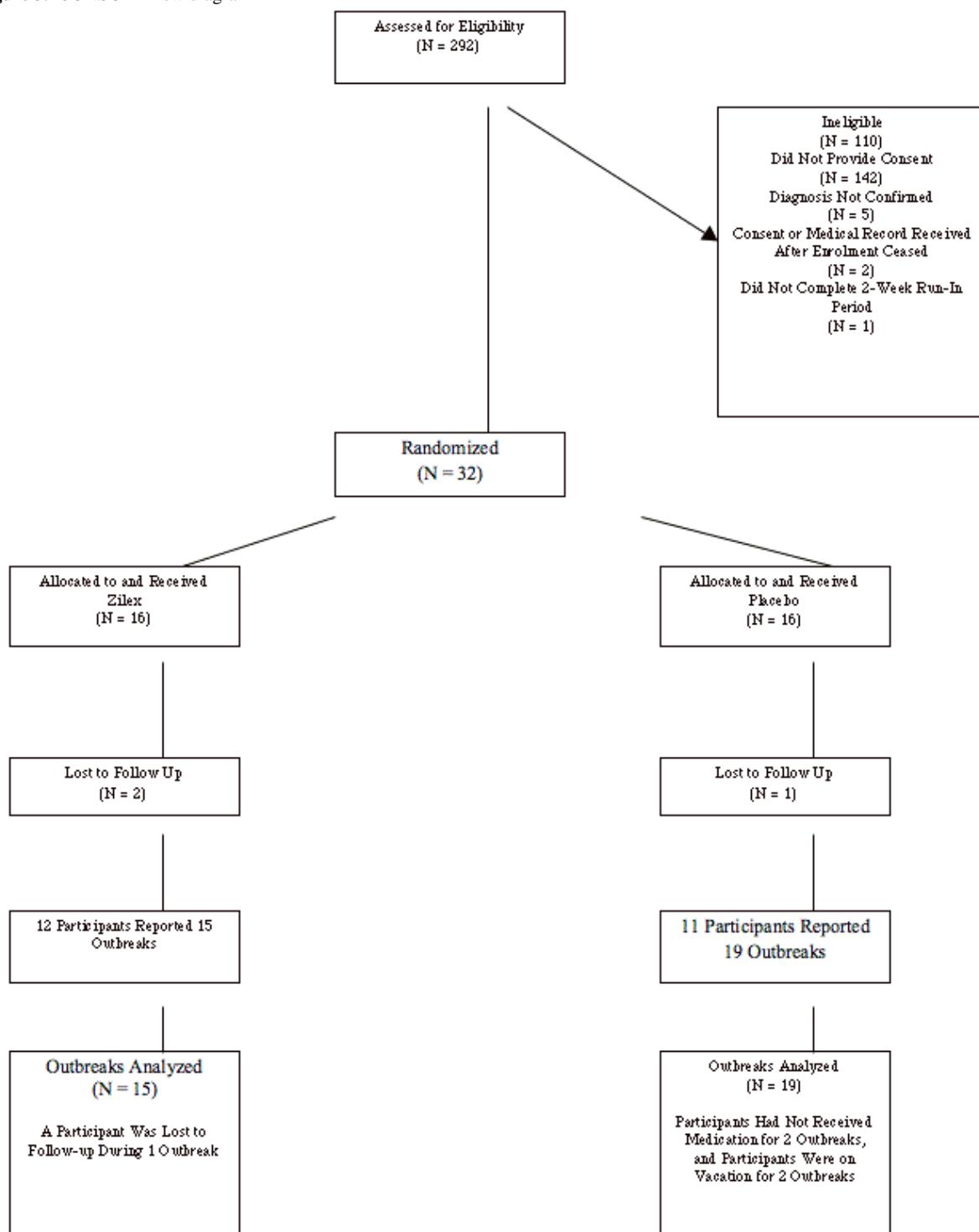
Table 1. Baseline characteristics of trial participants

	Participants Receiving DSS (N = 16) N (%)	Participants Receiving Placebo (N = 16) N (%)	P *
Female	9 (56.3)	14 (87.5)	.11
Region of the United States			
Northeast	7 (43.8)	6 (37.5)	.42
Southeast	2 (12.5)	5 (31.3)	
Midwest	5 (31.3)	2 (12.5)	
West	2 (12.5)	3 (18.8)	
Mean age (SD)	39.8 (10.5)	46.2 (13.4)	.14
Median age (IQ range)	44.5 (15)	51.5 (14)	

P values are based on 2-tailed Fisher exact tests for categorical outcome measures and a 2-tailed, unpaired t test with 30 degrees of freedom for mean age.

Figure 4. Duration and daily stage information for 32 cold sore outbreaks for which online data was available. Outbreaks 1-15 were treated with DSS, outbreaks 16-32 were treated with placebo. ? = missing data

Adherence to the study medication was similar in both groups, 7 (50%) of the DSS group reported using the cream at least every 2 hours compared to 6 (46.2%) in the placebo group; (*P*= .84). Most participants reported using the cream at least every 4 hours (78%) and all participants reported using the cream at least once per day during an outbreak. For 2 outbreaks,

participants had not yet received their study medication in the mail. Both groups were similar with respect to belief that they were taking the active cream, that the cream made their cold sores much better, helped abort their outbreaks, and worked as well or better than the creams used in the past (Table 3).

Table 2. Means of duration of outbreak, days to crust formation, sum of pain scores, sum of stage scores, sum of clusters, and sum of acetaminophen use by treatment group; adjusted for gender and age

	Outbreaks (N = 15) for Participants Receiving DSS	Outbreaks (N = 19) for Participants Receiving Placebo	P
Total duration of outbreak (days)	6.6	7.7	.24
Days to crust formation	3.5	4.9	.10
Sum of daily pain scores	3.1	7.6	.04
Sum of daily stage scores	17.5	17.9	.95
Sum of clusters	4.7	6.8	.24
Sum of acetaminophen tablets	1.1	0.5	.55
After exclusion of outbreaks requiring imputation			
Total duration of outbreak (days)*	6.3	8.2	.21
Days to crust formation†	3.5	5.0	.14

* Six and 8 outbreaks were excluded from the verum and placebo groups, respectively.

† Five and 7 outbreaks were excluded from the verum and placebo groups, respectively.

Table 3. Frequencies, percentages, and 2-tailed Fisher exact tests of categorical outcome measures

	DSS (N = 14) N (%)	Placebo (N = 13) N (%)	P
Reported use of cream as directed	7 (50.0)	6 (46.2)	.84*
Reported cream made cold sores "much better"	8 (57.1)	9 (69.2)	.69
Reported cream helped abort outbreak	9 (64.3)	10 (76.9)	.68
Reported belief that they are taking active cream	13 (92.9)	10 (76.9)	.33
Reported cream worked "as well or better than creams used in past"	10 (76.9)†	12 (92.3)	.59

* Chi-square test ($\chi^2_1 = 0.04$).

† Information was missing for 1 outbreak.

No adverse events were reported during the course of the trial via the adverse-event reporting form on the Web site, e-mail, or phone. However, several participants reported in questionnaires that:

- the cream tingled/burned on application: DSS (n = 1), placebo (n = 3)
- was numbing: DSS (n = 5), placebo (n = 1)
- was gritty: DSS (n = 1), placebo (n = 1)
- dried the lips: DSS (n = 1), placebo (n = 0)
- tasted bad: DSS (n = 1), placebo (n = 2)
- did not work: DSS (n = 0), placebo (n = 2)
- slid off the lip: DSS (n = 1), placebo (n = 0)
- "made the blisters spread more": DSS (n = 1), placebo (n = 0).

Discussion

The primary goal of this study was to evaluate the feasibility of conducting a clinical trial on the Internet that focused on outbreaks and required frequent participant contact. Certain aspects of this trial design proved to be robust. Participant recruitment was relatively easy; the interactive nature of the Web site with an eligibility questionnaire reduced the burden on the investigators of screening applicants, and we were able to exceed our recruitment goal in a short period of time (6 months). Overall participant retention in the trial was high; 29 (91%) of participants completed the trial. In addition, the reduction in pain seen in the verum group compared to the placebo group lends support to the internal validity of this approach, as Zilexcontains benzocaine, an anesthetic shown to be effective in pain reduction [8,9].

While we found recruitment to be unproblematic and overall participant retention high, there were several aspects of this clinical trial design that need refinement. While it is unclear whether this experience differs from traditional clinical trials [6], there were a number of outbreaks for which it was difficult to assign a total duration due to missing data. Many of the missed visits occurred during weekends and holidays. This pattern indicates the possibility that many participants were accessing the trial Web site from work, and may not have had access to the Internet at home. Future trials of this nature may benefit by requiring participants to have Internet access at home. In addition, our trial participants did not receive any compensation. It is conceivable that some form of compensation might improve compliance in this respect.

Another concern with the results of the trial was incomplete adherence to the study medication. It is unclear whether participants in a traditional clinic setting would have been more likely to use the study medication as directed. Poor adherence to study medication in clinical trials can have detrimental effects on the evaluation of safety and efficacy. On the other hand, the adherence rate found in this trial may be reflective of adherence to the medication in the general population and could, therefore, provide a valid evaluation of effectiveness.

Limited generalizability may be a potential limitation of an Internet-based trial design. Our participants were Internet users and might not be representative of all individuals with cold sores. While this could theoretically influence the generalizability of our findings, it should not impair the validity. Of course, hospital-based or clinic-based trials face similar problems in that their participants are frequently highly selected.

One of the primary benefits of an Internet-based design for a clinical trial requiring frequent participant contact is the reduced burden on participants. An alternative approach would be to augment this system using electronic data capture through wireless personal digital assistants (PDAs) [12].

As a feasibility study, this endeavor has been highly informative. In particular, it appears that even with the reduced participant burden inherent in the Internet-based approach, the goals of daily online visits and adherence to an every-2-hours dosing schedule pose significant challenges. Based on our experiences, we make the following recommendations for future such trials: (1) mail a supply of (masked) active and placebo to each participant at enrolment, (2) randomize outbreaks rather than participants, (3) use the Internet as a portal enhanced by wireless PDAs for frequent data capture, (4) program the PDAs to perform a reminder function for medication adherence, and (5) consider providing an incentive.

Acknowledgments

Conflicts of Interest

None declared.

Multimedia Appendix

Screenshots of the web-based interfaces for trial participants: [PPT File, 2.5MB - jmir_v6i1e6_app1.ppt]

References

1. Kelly MA, Oldham J. The Internet and randomised controlled trials. Int J Med Inform 1997 Nov;47(1-2):91-99. [Medline: 98165224] [doi: 10.1016/S1386-5056(97)00091-9]

2. Lenert LA, Looman T, Agoncillo T, Nguyen M, Sturley A, Jackson CM. Potential validity of conducting research on headache in internet populations. Headache 2002 Mar;42(3):200-203. [Medline: 21901190] [doi: 10.1046/j.1526-4610.2002.02052.x]

3. Salkowski A, Tromp G, Greb A, Womble D, Kuivaniemi H. Web-site-based recruitment for research studies on abdominal aortic and intracranial aneurysms. Genet Test 2001;5(4):307-310. [doi: 10.1089/109065701753617435] [Medline: 21958834]

4. Marks R, Bristol H, Conlon M, Pepine CJ. Enhancing clinical trials on the internet: lessons from INVEST. Clin Cardiol 2001 Nov;24(11 Suppl):V17-V23. [Medline: 21569192]

5. Mcalindon T, Formica M, Kabbara K, Lavalley M, Lehmer M. Conducting clinical trials over the internet: feasibility study. BMJ 2003 Aug 30;327(7413):484-487 [FREE Full text] [doi: 10.1136/bmj.327.7413.484] [Medline: 22827257]

6. Spruance SL, Rea TL, Thoming C, Tucker R, Saltzman R, Boon R. Penciclovir cream for the treatment of herpes simplex labialis. A randomized, multicenter, double-blind, placebo-controlled trial. Topical Penciclovir Collaborative Study Group. JAMA 1997 May 7;277(17):1374-1379. [Medline: 97280616] [doi: 10.1001/jama.277.17.1374]

7. Gong Y, Wen A, Cheung D, Sacks SL. Preclinical evaluation of docusate as protective agent from herpes simplex viruses. Antiviral Res 2001 Oct;52(1):25-32. [Medline: 21421030] [doi: 10.1016/S0166-3542(01)00156-5]

8. Rosa AL, Sverzut CE, Xavier SP, Lavrador MA. Clinical effectiveness of lidocaine and benzocaine for topical anesthesia. Anesth Prog 1999;46(3):97-99. [Medline: 21545493]

9.   Rosivack RG, Koenigsberg SR, Maxwell KC. An analysis of the effectiveness of two topical anesthetics. Anesth Prog 1990;37(6):290-292. [Medline: 91273272]

10. Microsoft Access [computer program]. URL: http://www.microsoft.com/ [accessed 2004 Jan 5]

11. Altman DG, Schulz KF, Moher D, Egger M, Davidoff F, Elbourne D, et al; CONSORT GROUP (Consolidated Standards of Reporting Trials). The revised CONSORT statement for reporting randomized trials: explanation and elaboration. Ann Intern Med 2001 Apr 17;134(8):663-694 [FREE Full text] [Medline: 21200944]

12. Koop A, Mösges R. The use of handheld computers in clinical trials. Control Clin Trials 2002 Oct;23(5):469-480. [Medline: 22280758] [doi: 10.1016/S0197-2456(02)00224-6]

Abbreviations

DSS: Dioctyl Sodium Sulfosuccinate
PDA: Personal Digital Assistant

Original Paper

Sex Differences in Youth-Reported Depressive Symptomatology and Unwanted Internet Sexual Solicitation

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Abstract

Background: As the number of youths using the Internet regularly increase, so too does the number of youths potentially vulnerable to negative experiences online. Clinicians, policy makers, and parents need to better understand the Internet and factors related to positive and negative experiences online.

Objective: Primarily to investigate the association between youth-reported depressive symptomatology and unwanted Internet sexual solicitation and secondarily to identify sex differences in related characteristics of affected youth.

Methods: Data from the Youth Internet Safety Survey were analyzed to investigate the association between reported depressive symptomatology and unwanted Internet sexual solicitation. The Youth Internet Safety Survey was a nationally-representative, cross-sectional telephone survey. Youth participants (N = 1501) were English speakers between the ages of 10 and 17 years who had accessed the Internet at least 6 times in the previous 6 months and had resided in the household for at least 2 weeks in the previous year. Eighty-two percent of contacted households agreed to participate. Each participant was asked to indicate whether any of the 9 symptoms of major depression defined by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) had been present within the previous month. Logistic regression was used to estimate the odds of reporting an unwanted sexual solicitation online for youths with mild or major depressive symptomatology versus no symptomatology. A parsimonious, multivariate model of significant youth characteristics was identified separately for males and females.

Results: Youths who report major depressive-like symptoms were 3.5 times more likely (odds ratio, 3.54; 95% confidence interval, 2.19-5.71) to also report an unwanted sexual solicitation online compared to youths with mild/no symptomatology. After adjusting for significant Internet and psychosocial characteristics, male Internet users who report major depressive-like symptomatology were 2.5 times more likely to also indicate an unwanted Internet solicitation (adjusted odds ratio, 2.72; 95% CI, 1.15-6.40); significant differences were not observed among otherwise-similar females. Further, among youths reporting an Internet solicitation (N = 283), youths with major depressive-like symptomatology were twice as likely to report feeling emotionally distressed by the incident compared to youths with mild/no symptomatology (odds ratio, 2.27; 95% CI, 1.03-5.02).

Conclusions: While the majority of youths report positive experiences online, some youths may be more vulnerable to negative experiences. Cross-sectional results indicate that the report of depressive symptomatology is significantly related to the concurrent report of an unwanted Internet sexual solicitation, especially for young males. Future research should focus on parsing out the temporality of events and identifying additional populations of vulnerable youths online.

KEYWORDS

Youth; Internet; depression; sexual solicitation; mental health

Introduction

An estimated 97% of youths between the ages of 12 and 18 use the Internet in the United States [1]. Although youths consistently report positive aspects of Internet use [2- 4], young people, parents, and politicians have raised concerns about the possible deleterious effects of exposure to negative sexual experiences online, including sexual material and pedophiles [2,5- 6]. Given the almost complete saturation of Internet use among children and adolescents, research about the experiences young people are having online and their effect on somatic and mental health is needed.

Unwanted online sexual solicitation is one such online experience that may affect the health and functioning of a young person. It occurs when a youth is encouraged to engage in sexual activity when he or she does not wish to. Specifically, it is being overtly persuaded to talk about sex with someone, doing something sexual, or disclosing personal sexual information when not wanted [2,7,8]. This may occur as part of "preening," during which an adult starts a nonsexual relationship with a child online to build trust and then segues into seducing the child into sexual acts [6]. It may also occur in a peer-to-peer exchange between 2 young people of similar age who are communicating online.

O'Connell (2003) [9] has conducted a qualitative analysis of online chat exchanges between herself, posing as a young girl, and predatory adults. Data were collected over 5 years. Findings reveal the truly-threatening aspects of online sexual solicitation for some young people. The data suggest that emotionally-vulnerable and socially-disconnected youths may be at greater risk for pedophilic targeting. The selection bias inherent in nonrandomly-selected case studies however, disallows inference and generalization to the online youth population, or comparisons between solicited and nonsolicited young people-both of which are necessary to inform future prevention and intervention research.

Berson et al [10] conducted a survey of adolescent girls who use the Internet in the effort to begin understanding their experiences of sexual solicitation online. The Web-based study included recruitment messages on Seventeen Magazine Online. Ten thousand eight hundred youths completed the online survey. Findings suggest that the anonymous nature of online exchanges may lead to wrong conclusions about the level of risk or safety an online acquaintance may represent. Indeed, some people prefer Internet-based relationships given the ease of deception this type of communication allows. While not all people who enjoy this anonymity have ill intent, there are those who take advantage of the inscrutability to prey on susceptible young people. Berson [11] notes that, although intimate and positive relationships are formed online by young people, the culture of "deception" in cyberspace conversations is a reason for concern with respect to vulnerable adolescent females. These results justify further examination of online sexual solicitation of youths, preferably with a randomly selected group of young people to allow the report of prevalence rates and comparisons of related characteristics.

A recent, nationally-representative telephone survey of youths in the United States between the ages of 12 and 17 indicates that 1 in 5 youths have been the target of an unwanted sexual solicitation within the previous year [12]. Personal characteristics associated with unwanted sexual solicitation include being female, older (ie, between 14 and 17 years of age), and psychosocially challenged [12]. Although most youths reporting an unwanted sexual solicitation also report little emotional harm, 25% reveal experiencing extreme emotional distress [12].

Despite the broad-ranging interest in exposure to sexual experiences among youths [2,6] , and indication that unwanted sexual solicitation is associated with emotional distress for one-quarter of those targeted [12], we know little about subpopulations that may be more vulnerable to sexual solicitation online. For example, there is a noticeable lack of information about how these experiences affect young people with mental health problems such as depression. Major depressive disorder affects an estimated 2% to 8% of youths at any given time [13]. There is a strong literature base that indicates traumatic events can lead to depressive symptomatology for children and adolescents [14]. It is possible then, that a sexual solicitation will be related to a subsequent onset of a major depressive episode. It is alternatively possible that young people with major depressive symptomatology are more susceptible to online solicitations [15]. Depressive symptomatology is in fact related to risk for unhealthy sexual experiences, specifically sexual abuse [16] and risky sexual behavior [17]. Given the significant personal distress and public health burden that is related to child and adolescent depression [18], it is vitally important that we begin to understand how unwanted sexual solicitation is related to this disorder. Establishing a baseline association between depressive symptomatology and unwanted sexual solicitation is a necessary first step in parsing out the relationship between mental health and the important public health phenomenon, Internet sexual solicitation.

Gap in Current Literature

Despite the extensive numbers of young people who are immersed in the Internet culture, researchers and clinicians continue to be disadvantaged by the paucity of research based upon representative samples of young people that analyze the interplay between psychosocial functioning and experiences youths have online. To begin addressing this gap, the current research will examine cross-sectional data to identify trends in the relationship between youth-reported depressive symptomatology and unwanted Internet sexual solicitation. We then examine gender-specific analyses to identify possible differences by sex as hypothesized based upon the reported differences in prevalence rates of depressive symptomatology [19,20] and sexual abuse [21,22]. Internet usage and psychosocial characteristics are examined for potential confounding of the observed relationships. Finally, the association between depressive symptomatology and self-reported sequelae of the unwanted sexual solicitation is estimated.

Methods

The Youth Internet Safety Survey (YISS) was a nationally-representative telephone survey of young, regular Internet users, and one caregiver in the household focusing on youth Internet harassment, unwanted sexual solicitation, and unwanted exposure to sexual material. Use of the YISS data was provided by Dr. David Finkelhor and colleagues at the University of New Hampshire Crimes Against Children Research Center. The cross-sectional survey was conducted between fall 1999 and spring 2000. Approved and supervised by the University of New Hampshire's Human Subjects Committee, the YISS was commissioned by the National Center for Missing and Exploited Children, supported by the Office of Juvenile Justice and Delinquency Prevention, and conformed to the Department of Justice's rules for research projects funded by the agency. Approval to perform the current data analyses was obtained by the Johns Hopkins Bloomberg School of Public Health's Committee for Human Research.

Study Population

Youth participants (N = 1501) were English speakers between the ages of 10 and 17 years who had accessed the Internet at least 6 times in the previous 6 months. Location of Internet access was broadly defined to include all possible locations (eg, home, library, another person's home) to ensure a variety of Internet users reflective of the general population of users. Additionally, youths were required to have resided in the household for at least 2 weeks in the previous year. The caregiver who was interviewed was self-identified as the one most knowledgeable about the youth's Internet activity. Informed consent from the caregiver was required before the commencement of his or her interview, and both caregiver and youth consented before the youth interview.

The sample characteristics have been reported previously [7,12]. The average age of respondents was 14.15 years. Fifty-two percent of youth respondents were male, and 69% of adult respondents were female. Three quarters of youth participants self-identified as white, with an additional 10% self-identifying as black. Seven percent of youth respondents self-identified as being of Hispanic ethnicity. One quarter of households reported a 1999 income of $75000 or higher and more than 1 in 5 reported the highest household education as being at least some college. These household characteristics were higher than the United States average [23], but were consistent with reports of households with Internet connections at the time of data collection [24,25].

Design and Procedures

Details of YISS sampling methods have been detailed elsewhere [12]. Phone numbers were first generated for the Second National Incidence Study of Missing, Abducted, Runaway, and Thrownaway Children [26], a nationally-representative telephone survey targeting United States youth. Phone numbers for households that were identified during their initial screening process as having at least 1 youth residing who was between the ages of 9 and 18 were forwarded to YISS researchers for future contact. A sample size of 1500 youth respondents was targeted before YISS data collection, in order to achieve a

sampling error of ±2.5% at the 5% significance level. Of the 72% of households that were contacted and eligible (N = 1857), 82% (N = 1501) completed both the youth and caregiver surveys.

Measures

Unwanted Sexual Solicitation

Three questions used in earlier investigations [7,12] were used to identify youths who had been sexually solicited online in the previous year: (1) whether anyone had asked the youth to talk about sex when he or she did not want to; (2) whether the youth had been asked to disclose personal, sexual information, such as sexual experiences or body type, about him or herself; and (3) whether anyone had asked the youth to do something sexual that he or she did not want to. Respondents who endorsed at least 1 of the 3 questions, as well as all solicitations that involved an adult (whether deemed "wanted" or "unwanted" by the young person) were considered to have been exposed to an unwanted sexual solicitation.

Depressive Symptomatology

Youths were asked 9 dichotomous (yes/no) questions based upon the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) definition of major depressive disorder [27]. Each referred to any time within the last month except for dysphoria, which referred to most of the day, nearly every day for the previous 2 weeks. Reflective of the DSM-IV criteria for major depression, 3 additional questions were asked about functional challenge, including self-efficacy, personal-hygiene, and schoolwork. Respondents were categorized into 1 of 3 categories: (1) major depressive-like symptomatology (ie, 5 or more symptoms, 1 of which was anhedonia or dysphoria, and functional impairment in at least 1 area); (2) minor depressive-like symptomatology (ie, at least 3 symptoms of depression); or (3) no/mild symptomatology (fewer than 3 symptoms).

Internet Usage Characteristics

Exploratory factor analysis identified a latent variable described as "interactive Internet activity." Each eigenvalue was greater than or equal to 1. Eigenvalues are commonly used as a useful tool to identify factors because they are related to the underlying factor's ability to explain the correlations between the observed variables included in the exploratory factor analysis. An eigenvalue of 1 is a widely-accepted cutoff when identifying factors. The variables included in this factor were:

- using the Internet (ever) for Instant messaging, e-mailing, downloading files, updating a Web page, connecting to a news group, visiting chat rooms, and looking up movie information
- logging onto the Internet from home versus all other places
- using the Internet 5 or more days a week
- self-rated Internet expert (almost or definitely) versus being less skilled
- importance of Internet to self (very, extremely) versus less importance.

Factor scores were used to categorize respondents into 1 of 3 groups:

1. highly interactive (1 or more SD above the mean)
2. average interactive (scores within 1 SD of the mean)
3. less than average (1 or more SD below the mean; reference group).

In addition, youths were asked to identify the activity for which they used the Internet most. This activity was grouped into 4 categories based upon frequency and speed of interaction:

1. chat rooms
2. e-mail
3. instant messaging
4. all else (reference group).

Finally, youths who reported online aggression towards another person were identified by their engaging in at least 1 of 2 Internet harassment activities:

1. making rude or nasty comments to someone else online
2. harassing or embarrassing someone else on the Internet.

Substance Use

Youth respondents were asked about the frequency of 5 types of substance use in the previous year, including: tobacco, alcohol, inhalants, marijuana, and all other drugs. Each was dichotomized (4 or more times versus fewer) to put the variables on the same scale as other variables included in the exploratory factor analysis. One factor was identified (eigenvalue greater than or equal to 1), which included all 5 variables. Because of the data distribution of the sum of the 5 variables, total scores were categorized into 3 groups:

1. low users (1 or more SD below the mean; reference group)
2. average users (scores within 1 SD of the mean)
3. heavy users (1 or more SD above the mean).

Life Challenge

Indication of life challenge was also included because of its association with depressive symptoms [28]. Thus, interpersonal challenge was noted for young people who reported 2 or more versus fewer of the following events:

- being attacked by 1 person
- being attacked by a gang
- having something stolen from the young people
- being hit by a peer
- by being "picked on" by a peer in the previous year.

Further, 2 or more life challenges (range, 0-4) in the previous year included the following experiences:

- death in the immediate family
- moving to a new community
- caregiver divorce
- loss of job among the caregivers in the previous year.

Data Analysis

For the purposes of the current investigation, cases included in the analyses were required to have valid data for the majority of variables assessed. Records missing more than 2 variables within a subcategory of analytic interest (ie, depressive symptomatology, Internet use, demographics, negative life experiences, substance use), or those missing 2 variables across

2 or more subcategories, were dropped. Nine cases met these criteria and were excluded from further analyses. Additionally, factor scores could not be estimated for 3 cases because of unstable estimates, resulting in a final sample size of 1498 youth.

Missing values were imputed to maximize available data using best-set regression techniques [29]. Values were estimated based upon responses for depressive symptoms, unwanted Internet experiences (ie, sexual solicitation and Internet harassment), race, age, and sex; in most cases, this involved less than 1% of cases. "Don't know" and "refused" responses were coded at the variable mean, and therefore most often as "symptom absent." In most instances, this affected less than 1% of all cases. Finally, 3 separate "dummy" variables were created to reflect whether data for each case had been manipulated by (1) imputation, (2) recoding for "don't know," or (3) recoding for "refused" response.

MPlus was used to estimate several hypothesized latent variables [30]. All variables were included in 1 exploratory factor analysis to adjust for unanticipated cross correlations across hypothesized factors. The final factor solution was identified based upon the combination of eigenvalues, scree plots, and root mean square residuals. Scores were estimated using varimax rotation. Seven factors were identified: Internet use, substance use, depressive symptomatology, and 4 aspects of the caregiver-child relationship (not included in the current analyses).

Using Stata 7 [29], bivariate relationships between variables were assessed using the chi-square statistic. Logistic regression modeling was used to estimate the odds of reporting an unwanted sexual solicitation online for youths who report major or minor depressive-like symptomatology versus mild/no symptomatology. Upon observation that the association between depressive symptomatology and Internet sexual solicitation was different for males and females, the sample was stratified and a parsimonious logistic regression model of significant factors was developed separately for each sex. Two additional youth characteristics were investigated for effect modification: substance use [15,31] and age [32,33].

A saturated logistic regression model, including all youth characteristics and interaction terms, was first fit. Variables were then deleted based upon backward stepwise and forward stepwise tests for significance ($P < .1$). Variables identified in either stepwise solution were then entered into one model and tested for significant contribution to the overall model based upon likelihood ratio tests ($P < .05$). Depressive symptomatology and the 3 dummy variables (ie, indication of a refused response, don't know response, and imputed variable) were retained in the final model regardless of significance. Each final model was tested for goodness of fit using the Hosmer-Lemeshow goodness-of-fit test ($P < .5$ indicates better fit). All regression analyses were performed using the Stata statistical analysis package [29].

Results

Descriptive Results

In the current study, 12% (N = 94) of male and 27% (N = 189) of female young regular Internet users reported at least 1

unwanted sexual solicitation in the previous year. Five percent (N = 77) of young regular Internet users met criteria for major depressive-like symptomatology in the previous month. An additional 14% (N = 211) met criteria for minor depressive-like symptoms. Females were 60% more likely (OR = 1.59; 95% CI, 1.00-2.54) (OR = odds ratio, CI = confidence interval) to report major depressive-like symptomatology compared to males, although no sex differences were observed for youths with minor depressive-like symptomatology versus no depressive symptoms (OR = 0.91; 95% CI, 0.68-1.22). The odds of major depression-like symptomatology increased 19% with each year in age of the respondent (OR = 1.19; 95% CI, 1.05-1.35), while no significant differences in the odds of minor depressive-like symptomatology were indicated by age (OR = 1.0; 95% CI, 0.92-1.07).

Eleven percent of youths reporting an unwanted online sexual solicitation also reported major depressive-like symptomatology as compared to 3.7% of youths who were not solicited (χ^2_1= 26.8, P< .001). Similarly, 17.7% of youths who indicated sexual solicitation online also reported minor depressive-like symptoms compared to 13.4% of youths indicating no solicitation event (χ^2_1= 3.5, P= .06). Further, among youths who report an unwanted sexual solicitation online (N = 283), those meeting criteria for major depressive-like symptomatology were more than twice as likely (OR = 2.27; 95% CI, 1.03-5.02) to indicate they felt emotionally distressed by the incident compared to youths with mild/no symptoms of depression.

Reports From Male Internet Users

The most parsimonious logistic regression model of significant factors related to the report of unwanted sexual solicitation online for males (N = 782) is found in Table 1. Acceptable model fit was indicated for the parsimonious model (Hosmer-Lemeshow goodness of fit χ^2_7= 1.6, P= .98). Effect modifications of the relationship between solicitation and depressive symptomatology by substance use and age were explored but resulted in unstable estimates and were not included in the steps for building the final model. Final estimates were adjusted for the effects of "don't know," refused, and imputed responses; however, these did not differ significantly from the unadjusted estimates.

Table 1. Final logistic regression model of significant characteristics associated with unwanted Internet sexual solicitation for Male Internet users (N = 782)

Male Youth Characteristics	Adjusted Odds Ratio* (95% Confidence Interval)	P
Depressive symptoms		
Symptoms of major depression	2.72 (1.15, 6.40)	.02
Symptoms of minor depression	0.89 (0.45, 1.77)	.74
Mild/Absent symptoms	1.00 (reference group)	
Internet usage characteristics		
Interactive Internet use		
Frequent	4.80 (2.47, 9.35)	< .001
Moderate	2.13 (1.16, 3.94)	.02
Infrequent	1.00 (reference group)	
Most frequent Internet activity		
Chat room	3.13 (1.60, 6.11)	< .001
E-mail	1.57 (0.84, 2.94)	.16
Instant Messaging	1.10 (0.52, 2.32)	.80
All other	1.00 (reference group)	
Harasser of others online	1.80 (1.01, 3.20)	.05
Psychosocial characteristics		
Life challenge ($\geq$ 2)	2.94 (1.33, 6.50)	.01
Interpersonal victimization ($\geq$ 2)	1.87 (1.12, 3.14)	.02

* Adjusted odds ratio = the odds ratio estimated after adjusting for all other variables included in the parsimonious model.

Males who reported symptoms of major depression were almost 6 times as likely (OR = 5.90; 95% CI, 2.79-12.49) to report an unwanted Internet sexual solicitation compared to males indicating mild/absent symptoms of depression. No significant differences were observed however, between males who indicated minor depressive-like symptomatology, and mild/absent symptoms of depression (OR = 1.29; 95% CI, 0.71-2.36). After adjusting for all other significant characteristics, males who reported symptoms of major depression were almost 3 times as likely (adjusted OR = 2.72; 95% CI, 1.15-6.18) to also report an unwanted sexual solicitation compared to otherwise-similar males who reported mild/absent

symptoms of depression (see Table 1). (Adjusted odds ratio is the odds ratio estimated after adjusting for all other variables included in the parsimonious model.)

In addition to depressive symptomatology, interactive Internet activity, using the Internet most frequently for logging onto chat rooms, and harassing others online were associated with increased odds of reporting an unwanted Internet sexual solicitation among males after adjusting for other significant characteristics (see Table 1). Multiple psychosocial indicators, including life challenge and interpersonal victimization also were significantly related to the odds of reporting an unwanted sexual solicitation for males.

Reports From Female Internet Users

A parsimonious logistic regression model of significant factors related to the report of unwanted sexual solicitation online for females (N = 707) is in Table 2. Acceptable model fit was indicated for the final logistic regression model (Hosmer-Lemeshow goodness of fit $\chi^2_{204} = 6.4$, $P = .60$). We were unable to determine whether substance use and age affected these relationships because analyses produced unstable estimates. The final model estimates were adjusted for the effects of don't know, refused, and imputed responses, although unadjusted results did not differ. Young regular Internet-using females who reported symptoms of major depression were twice as likely to also report an unwanted sexual solicitation online (OR = 2.33; 95% CI, 1.25-4.35), while females who reported symptoms of minor depression were 80% more likely (OR = 1.83; 95% CI, 1.16-2.90) to indicate an Internet event compared to females indicating mild/absent symptoms of depression. After controlling for other significant characteristics, a trend for increased odds of reporting Internet sexual solicitation was still observed for females reporting minor or major depressive symptoms, although it was no longer statistically significant.

Table 2. Final parsimonious model of significant characteristics associated with unwanted Internet sexual solicitation for female Internet users (N = 707)

Female Youth Characteristics	Adjusted Odds Ratio (95% Confidence Interval)	P
Depressive symptoms		
Symptoms of major depression	1.40 (0.65, 2.99)	.39
Symptoms of minor depression	1.62 (0.96, 2.76)	.07
Mild/Absent symptoms	1.00 (reference group)	
Internet usage characteristics		
Harasser of others online	4.07 (2.48, 6.68)	< .001
Interactive Internet use		
High	3.21 (1.79, 5.77)	< .001
Moderate	2.12 (1.34, 3.37)	< .001
Infrequent	1.00 (reference group)	
Most frequent Internet activity		
Chat room	3.10 (1.62, 5.93)	< .001
Instant Messaging	1.34 (0.68, 2.62)	.39
E-mail	1.30 (0.81, 2.07)	.28
All other	1.00 (reference group)	
Psychosocial characteristics		
Substance use		
High user	2.87 (1.13, 7.34)	.03
Average user	2.09 (0.97, 4.53)	0.06
Mild/non-user	1.00 (reference group)	
Interpersonal victimization ($\geq$ 2)	1.82 (1.15, 2.89)	0.01

Multiple Internet usage characteristics, including harassing others, using the Internet for interactive Internet activities, and using the Internet most frequently for chat room use, were related to the likelihood of reporting an unwanted sexual solicitation for female Internet users after adjusting for other influential factors (see Table 2). Substance use and interpersonal victimization were also related to significantly higher odds of

also reporting an unwanted sexual solicitation online among otherwise similar female Internet users.

Additional covariates that were tested but found not to be significantly associated with the report of sexual solicitation online after adjusting for depressive symptomatology included: type of Internet service provider, average daily Internet usage, sexual or physical abuse, the number of close friends, the

number of times a youth spent time with friends outside of school in a typical week, household income, age, and race and ethnicity. Also, separate models for each of the 3 outcomes of unwanted Internet sexual solicitation, ie, being encouraged to discuss sexual topics, being encouraged to engage in sexual behavior, and being encouraged to divulge personal sexual information, were constructed to check for consistency of association with reported depressive symptomatology. In each model, depressive symptomatology was related to significantly greater odds of unwanted solicitation, thus supporting the use of the combined solicitation outcome in our analyses.

Discussion

Unwanted Internet sexual solicitation is reported frequently by young regular Internet users. Almost 1 in 3 females (27%) and 1 in 10 males (12%) indicate they have been approached in the previous year. These cross-sectional results indicate a trend for self-reported depressive symptomatology to be associated with the concurrent odds of indicating an online solicitation. Findings suggest that the report of symptoms of major depression is associated with a 3-fold increase in odds of concurrently reporting an event. Sex-specific differences are noted, revealing that this association is especially strong for males. Males who report major depressive symptoms are almost 6 times as likely to also indicate an unwanted sexual solicitation compared to males reporting mild/absent symptoms of depression after adjusting for significant confounders. On the other hand, females reporting major depressive symptoms are twice as likely to indicate an unwanted sexual solicitation versus females reporting mild/absent symptoms.

Underlying differences in Internet use and psychosocial challenge explain the association between depressive symptomatology and the unwanted Internet solicitation among females. Among otherwise-similar males however, a continued association between major depressive symptomatology and unwanted sexual solicitation is observed. This is especially intriguing, for it implies that differences in Internet usage (eg, frequenting chat rooms), do not sufficiently explain variation in the odds of reporting an unwanted online sexual solicitation for males. These cross-sectional results raise an intriguing question for future research: are males more likely to experience depressive symptomatology because of the event, or is it that males who are experiencing depressive symptomatology are more likely to be targeted, or more probably, is the relationship bidirectional?

The especially-strong association between depressive symptomatology and Internet sexual solicitation among males may be because they are less prepared to handle an advance. More than twice as many females are the target of unwanted sexual solicitation, and it is possible that some male victims see themselves as being singled out for something that "should" be directed to females. It may be also that males receive less emotional support following the event, either because they are reticent to talk about it with potentially-ridiculing peers, or because others dismiss the emotional impact of the event, assuming that it must be less upsetting or even gratifying for the male. In either scenario, the sexual solicitation is experienced

as a traumatic event for males and may be a contributing factor for subsequent depressive symptomatology. Irrespective of temporality, these results indicate that health professionals need to be especially attuned to the Internet experiences of young men with depressive symptomatology.

Psychosocial Challenge

Psychosocial challenge is associated with the report of unwanted sexual solicitation online. Beyond major depressive-like symptomatology, results suggest that multiple life challenges and interpersonal victimization are each concurrently related to the report of unwanted Internet sexual solicitation for males. Females who report unwanted sexual solicitation also indicate psychosocial challenge; specifically, high substance use and interpersonal victimization are each associated with elevated odds of reporting an unwanted sexual solicitation. Thus, a youth's indication of multiple mental health-related problems is associated with also reporting sexual solicitation online for both sexes. Future research should focus on understanding why depressive symptomatology is part of the picture of challenge for males but not for females.

Drawing upon theories of depression, the profile of multiple and varied victimization experiences may reflect a type of "learned helplessness" [34] for boys who are manifesting depressive symptomatology. They may be less likely to be assertive and self-protective, thereby increasing the chances of exploitation. If true, the consequence appears to be multiple victimizations, including Internet sexual solicitation and offline bullying.

Emotional Distress

Although a cross-sectional study, youths who reported an unwanted sexual solicitation were queried about how they felt as a direct result of the event, thereby allowing temporal inference. One quarter of youths who report online solicitations indicate they feel very or extremely upset or afraid as a result [7]. The current investigation indicates that the report of depressive symptomatology is associated with 2-fold increased odds of reporting emotional distress due to the solicitation incident for youths who indicate major depressive-like symptoms compared to youths with mild/no symptoms. Given that the accumulation of negative life events is related to an increased risk of the onset of a major depressive episode among youths [14], it is possible that this negative experience will be related to an increased risk for subsequent depressive symptoms. It is also possible that youths with depressive symptoms are not only more likely to be solicited online, but also to be emotionally affected by the incident. Future longitudinal studies are needed to further understand this important association.

Cognitive Distortion

Some may conjecture that the observed relationship between reported depressive symptomatology and indications of sexual solicitation are perhaps a matter of cognitive distortion. Youths with depressive symptomatology are generally more likely to cognitively bias their perceptions of events in a negative manner [35]. Their perception of events may be skewed such that, what other young people view as neutral or mildly annoying, young people with depressive symptoms perceive as threatening or

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emotionally upsetting. Thus, youths indicating symptoms of depression are more likely to report an unwanted sexual solicitation simply because they are more likely to perceive an interaction as solicitous and personally threatening. Differences in interpretation and reaction to online events are certainly areas for future research; the current data do not allow disentanglement. What is revealed from the current results however, is that, whether due to cognitive distortion or not, almost 40% of young people who report major depressive symptomatology also report feeling very or extremely upset or afraid as a direct result of an unwanted sexual solicitation compared to 21% of young people who report mild/absent symptoms of depression (P< .05). Further, recent research about the grooming of children for cyber-victimization [9,10] indicates that it is vitally important that online sexual solicitation be neither marginalized nor viewed as a contrived problem. Transcripts from online dialogues convey the truly-threatening aspects of some of these interchanges [9]. The fact that depressive symptomatology and unwanted sexual solicitation are cross-sectionally related reveals an emerging public health and mental health issue that warrants further investigation.

Pedophilia or Peer-to-Peer Sexual Solicitation

The majority of research about online sexual solicitation has focused on adult-to-child solicitation and predation [9,11,36]. Although this is clearly an important health topic, this should not overshadow the fact that adolescent peers are soliciting each other. Almost half (48%) of YISS respondents who indicate they have been targeted for unwanted sexual solicitation report that the solicitor is less than 18 years of age [12]. About one quarter (24%) of solicitors are reported by the targeted YISS respondent to be over 18 years of age, and the remaining 27% of incidents involve a solicitor of unknown age. It is possible that an adult posing as a child, thus leading the young person to believe the solicitor was less than 18 years of age, is the real perpetrator in some of these incidents. It is also possible that peers carry out unwanted sexual solicitation on each other. Just as adolescents commit traditional sexual assault on their peers, it is likely that adolescents perpetrate unwanted sexual solicitation online towards their peers. This type of victimization must be acknowledged in Internet-based sexual solicitation discourse and must be discussed in intervention or prevention materials aimed at young people.

Limitations

Although the YISS is the largest, most detailed survey of young regular Internet users to date, it is not without limitations. First, the cross-sectional nature of the study precludes inferences about temporality. Nothing can be inferred regarding the causal relationship between depressive symptoms and unwanted sexual solicitation. This important baseline association however, justifies future research endeavors aimed at parsing out the relationship between depression and Internet sexual solicitation, as well as youth-oriented prevention programs. Second, a validated scale for major depressive disorder (MDD) was not

used to measure symptoms. Because the variables were based directly upon the DSM-IV criteria for major depressive disorder, it can be concluded that youths are experiencing depressive symptomatology, but they do not necessarily meet the criteria for disorder. Third, it is possible that the report of sexual solicitation was underreported, or that the severity of the experience was downplayed by the adolescent because he or she was concerned that others might be listening to the conversation. Researchers were aware of this possibility however, and encouraged youths to identify a time to conduct the interview when they would feel comfortable to disclose private and personal information [12]. All attempts were made to ensure the youth was in a private environment. Interviewers offered to call back at a more convenient time if the respondent was concerned about confidentiality. Finally, the exclusion of non-English speaking youths disallows the generalization to youths of other cultures.

Implications

Despite limitations, the current investigation contributes to the knowledge base of youth-related mental health issues and Internet experiences. For youths who indicate major depressive-like symptomatology, we found an increased likelihood of also reporting an unwanted sexual solicitation online. Further, these youths are likely experiencing multiple challenges, including negative life experiences and substance use. It is imperative that health professionals, policy makers, and parents are well versed on the activities youths are engaging in online; this seems to be especially true for mental health practitioners given the multitude of personal challenges reported. Future studies should also look at the association between mental health and susceptibility to "preening," a more-subtle yet dangerous form of online sexual solicitation [6].

Conclusions

The current study examines cross-sectional data to provide the necessary initial report of associations and trends to justify future research. Findings suggest that for males, differences in Internet usage alone are not sufficient to explain the odds of reporting an unwanted online sexual solicitation. Further, young people reporting solicitation online are likely experiencing significant psychosocial challenge, including depressive symptomatology for males, interpersonal victimization, and substance use for females. Additional education about the Internet is necessary to ensure youths affected by negative online experiences are appropriately identified.

The Internet is a pervasive mode of peer interaction in the lives of young people today. The linkages between online experiences and mental health, as both conferred vulnerability as well as related sequelae, must therefore be foremost in the minds of child public health researchers and providers. Understanding the complex interaction between mental health and online interactions, especially the influence of malleable characteristics such as Internet usage and psychosocial challenge, is an important area of emerging research.

Acknowledgments

Conflicts of Interest

None declared.

References

1. ; UCLA Center for Communication Policy. UCLA Internet Report: Year Three. Los Angeles, CA: UCLA Center for Communication Policy; 2003.
2. Lenhart A. Teenage life online: The rise of the instant-message generation and the Internet's impact on friendships and family relationships. Washington, DC: Pew Internet & American Life Project; Jun 20, 2001. URL: http://www.pewinternet.org/reports/toc.asp?Report=36
3. Borzekowski DL, Rickert VI. Adolescent cybersurfing for health information: a new resource that crosses barriers. Arch Pediatr Adolesc Med 2001 Jul;155(7):813-817. [Medline: 21328631]
4. Rideout V. Generation Rx.com: how young people use the Internet for health information. A Kaiser Family Foundation survey. URL: http://www.kff.org/entmedia/20011211a-index.cfm [accessed 2004 Jan 30]
5. ; Federal Trade Commission. Children's online privacy protection rule; final rule. Federal Register 1999;64(212):59887-59915 [FREE Full text]
6. Deirmenjian JM. Pedophilia on the Internet. J Forensic Sci 2002 Sep;47(5):1090-1092. [Medline: 22240557]
7. Mitchell KJ, Finkelhor D, Wolak J. Risk factors for and impact of online sexual solicitation of youth. JAMA 2001 Jun 20;285(23):3011-3014. [Medline: 21303927] [doi: 10.1001/jama.285.23.3011]
8. Stahl C, Fritz N. Internet safety: adolescents' self-report. J Adolesc Health 2002 Jul;31(1):7-10. [Medline: 22086113] [doi: 10.1016/S1054-139X(02)00369-5]
9. O'connell R. A typology of child cyberexploitation and online grooming practices. 2003. URL: http://image.guardian.co.uk/sys-files/Society/documents/2003/07/24/Netpaedoreport.pdf [accessed 2004 Jan 30]
10. Berson IR, Ferron JM. Emerging risks of violence in the digital age: lessons for educators from an online study of adolescent girls in the United States. J School Violence 2002;1(2):51-72. [doi: 10.1300/J202v01n02_04]
11. Berson IR. Grooming cybervictims: the psychosocial effects of online exploitation for youth. J School Violence 2003;2(1):5-18. [doi: 10.1300/J202v02n01_02]
12. Finkelhor D, Mitchell KJ, Wolak J. Online victimization: a report on the nation's youth. 2000 Jun. URL: http://www.missingkids.com/en_US/publications/NC62.pdf [accessed 2004 Jan 30]
13. Kessler RC, Walters EE. Epidemiology of DSM-III-R major depression and minor depression among adolescents and young adults in the National Comorbidity Survey. Depress Anxiety 1998;7(1):3-14. [Medline: 98254981] [doi: 10.1002/(SICI)1520-6394(1998)7:1<3::AID-DA2>3.0.CO;2-F]
14. Cohen LH, Burt CE, Bjorck JP. Life stress and adjustment: effects of life events experienced by young adolescents and their parents. Dev Psychol 1987;23(4):583-592. [doi: 10.1037//0012-1649.23.4.583]
15. Lewinsohn PM, Hops H, Roberts RE, Seeley JR, Andrews JA. Adolescent psychopathology: I. Prevalence and incidence of depression and other DSM-III-R disorders in high school students. J Abnorm Psychol 1993 Feb;102(1):133-144. [Medline: 93171410] [doi: 10.1037//0021-843X.102.1.133]
16. Boney-mccoy S, Finkelhor D. Is youth victimization related to trauma symptoms and depression after controlling for prior symptoms and family relationships? A longitudinal, prospective study. J Consult Clin Psychol 1996 Dec;64(6):1406-1416. [Medline: 97145773] [doi: 10.1037//0022-006X.64.6.1406]
17. Shrier LA, Harris SK, Sternberg M, Beardslee WR. Associations of depression, self-esteem, and substance use with sexual risk among adolescents. Prev Med 2001 Sep;33(3):179-189. [doi: 10.1006/pmed.2001.0869] [Medline: 21414281]
18. ; US Department of Health and Human Services. Mental health culture, race, and ethnicity : a supplement to Mental health, a report of the Surgeon General : executive summary (SuDoc HE 20.402:M 52/2/SUPP./EXEC.SUM./2001). Rockville, MD: Dept. of Health and Human Services, U.S. Public Health Service; 1999. URL: http://www.surgeongeneral.gov/library/mentalhealth/home.html
19. Cole DA, Tram JM, Martin JM, Hoffman KB, Ruiz MD, Jacquez FM, et al. Individual differences in the emergence of depressive symptoms in children and adolescents: a longitudinal investigation of parent and child reports. J Abnorm Psychol 2002 Feb;111(1):156-165. [Medline: 21855009] [doi: 10.1037//0021-843X.111.1.156]
20. Rushton JL, Forcier M, Schectman RM. Epidemiology of depressive symptoms in the National Longitudinal Study of Adolescent Health. J Am Acad Child Adolesc Psychiatry 2002 Feb;41(2):199-205. [Medline: 21824767] [doi: 10.1097/00004583-200202000-00014]
21. Nolen-hoeksema S, Girgus JS. The emergence of gender differences in depression during adolescence. Psychol Bull 1994 May;115(3):424-443. [Medline: 94286764] [doi: 10.1037//0033-2909.115.3.424]

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22.   Feiring C, Taska L, Lewis M. Age and gender differences in children's and adolescents' adaptation to sexual abuse. Child Abuse Negl 1999 Feb;23(2):115-128. [Medline: 99173504] [doi: 10.1016/S0145-2134(98)00116-1]

23.   ; US Census Bureau. United States Census 2000. URL: http://www.census.gov/main/www/cen2000.html [accessed 2004 Jan 30]

24.   ; National Public Radio, Kaiser Family Foundation, Kennedy School of Government. National survey of American adults on technology / National survey of American kids on technology. 2000. URL: http://www.npr.org/programs/specials/poll/technology/ [accessed 2004 Jan 30]

25.   Lebo H. The UCLA Internet report 2001 - Surveying the digital future: year two. 2001 Nov. URL: http://www.ccp.ucla.edu/pdf/UCLA-Internet-Report-2001.pdf [accessed 2004 Jan 30]

26.   Hammer H, Finkelhor D, Sedlak AJ. NISMART-2 household survey methodology technical report. Washington, DC: US Department of Justice, Office of Justice Programs, Office of Juvenile Justice and Delinquency Prevention; 2002.

27.   Association AP. Diagnostic and Statistical Manual of Mental Disorders DSM-IV. Washington, DC: American Psychiatric Association; Jan 15, 1994.

28.   Kazdin AE, Marciano PL. Childhood and adolescent depression. In: Mash EJ, Barkley RA, editors. Treatment of Childhood Disorders. New York: The Guilford Press; Jul 3, 1998.

29.   ; Stata Corp. Stata Statistical Software [computer program]. URL: http://www.stata.com/ [accessed 2004 Jan 30]

30.   Muthen LK. Mplus: Statistical analysis with latent variables : user's guide. Los Angeles: Mutheìn & Muthìn; 1998.

31.   Anderson JC, Williams S, Mcgee R, Silva PA. DSM-III disorders in preadolescent children. Prevalence in a large sample from the general population. Arch Gen Psychiatry 1987 Jan;44(1):69-76. [Medline: 87099216]

32.   Carlson GA, Kashani JH. Phenomenology of major depression from childhood through adulthood: analysis of three studies. Am J Psychiatry 1988 Oct;145(10):1222-1225. [Medline: 88338787]

33.   Fleming JE, Offord DR. Epidemiology of childhood depressive disorders: a critical review. J Am Acad Child Adolesc Psychiatry 1990 Jul;29(4):571-580. [Medline: 90354323]

34.   Abramson LY, Seligman ME, Teasdale JD. Learned helplessness in humans: critique and reformulation. J Abnorm Psychol 1978 Feb;87(1):49-74. [Medline: 78171987] [doi: 10.1037//0021-843X.87.1.49]

35.   Quiggle NL, Garber J, Panak WF, Dodge KA. Social information processing in aggressive and depressed children. Child Dev 1992 Dec;63(6):1305-1320. [Medline: 93076611]

36.   O'connell R. Be somebody else but be yourself at all times: degrees of indentity deception in chatrooms. 2001. URL: http://www.once.uclan.ac.uk/docs/deception.doc [accessed 2004 Jan 30]

Abbreviations

CI: confidence interval
DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
OR: odds ratio
YISS: Youth Internet Safety Survey

The Internet as a Vehicle to Communicate Health Information During a Public Health Emergency: A Survey Analysis Involving the Anthrax Scare of 2001

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Abstract

Background: The recent public health risks arising from bioterrorist threats and outbreaks of infectious diseases like SARS (Severe Acute Respiratory Syndrome) highlight the challenges of effectively communicating accurate health information to an alarmed public.

Objective: To evaluate use of the Internet in accessing information related to the anthrax scare in the United States in late 2001, and to strategize about the most effective use of this technology as a communication vehicle during times of public health crises.

Methods: A paper-based survey to assess how individuals obtained health information relating to bioterrorism and anthrax during late 2001. We surveyed 500 randomly selected patients from two ambulatory primary care clinics affiliated with the Brigham and Women's Hospital in Boston, Massachusetts.

Results: The response rate was 42%. While traditional media provided the primary source of information on anthrax and bioterrorism, 21% (95% CI, 15% - 27%) of respondents reported searching the Internet for this information during late 2001. Respondents reported trusting information from physicians the most, and information from health websites slightly more than information from any traditional media source. Over half of those searching the Internet reported changing their behavior as a result of information found online.

Conclusions: Many people already look to the Internet for information during a public health crisis, and information found online can positively influence behavioral responses to such crises. However, the potential of the Internet to convey accurate health information and advice has not yet been realized. In order to enhance the effectiveness of public-health communication, physician practices could use this technology to pro-actively e-mail their patients validated information. Still, unless Internet access becomes more broadly available, its benefits will not accrue to disadvantaged populations.

KEYWORDS

Introduction

The public may be more aware of the dangers of infectious diseases today than in any other era in recent history. The possibility of bioterrorism has become a real concern, as has preventing and controlling the spread of naturally occurring outbreaks such as the recent SARS (severe acute respiratory syndrome) epidemic. The current global environment, where travel brings diverse and distant individuals into close proximity within a matter of hours, also allows for the accidental transportation of harmful microorganisms that until relatively recently remained more geographically isolated. This context means that public health authorities and the public face a set of unique health risks, especially in a time of crisis [1]. One such crisis occurred in October 2001 when anthrax spores were spread via the US postal system, alarming a public already anxious due to the September 11th terrorist attacks. Although investigation ultimately revealed that only four letters containing anthrax had entered the postal system, this relatively small-scale dispersion generated confusion and panic among the public and the media, and illustrated the challenge of communicating information about risk and reality to an alarmed public.

During the anthrax threat, the traditional media presented the public with an enormous amount of information on the emerging events, but the information provided was extremely variable, often shallow, and not always validated by health authorities. While some public health authorities endeavored to communicate evidence-based facts, other coverage simultaneously offered conflicting and often confusing accounts of what was happening, as well as varying advice on the dangers of anthrax and how to protect oneself [2]. Such a context made it difficult for the public to decide which sources to trust and what advice to follow [3]. Research has shown that individuals view physicians as very trustworthy sources of information, [4,5,6] yet most of the information regarding anthrax that was available to the public came through sources such as television news reports and newspapers, and this information was often not backed or reviewed by physicians.

In addition to traditional media sources, Internet websites (public and private) provided a complementary source of health information. Individuals often use the Internet to validate and expand upon information they have read or heard elsewhere [7]. However, there is little information on people's searching behavior or on how they are influenced by the material they find. We hypothesized that during the anthrax scare of 2001 at least a small segment of the population benefited from Internet information on emerging events, and that this kind of information was useful in advising people about appropriate behavior. If this was the case, how can this technology be leveraged to have a broader effect? What are strategies to facilitate wider use, and to ensure public access to quality Internet information? What is the Internet's place in the public health response to an emergency such as the anthrax scare? We designed a survey to further explore these questions with the ultimate goal of understanding how the Internet could best be used as a communication vehicle during a public health crisis.

Methods

This study was approved by the Partners HealthCare institutional review board. A survey was designed to assess how individuals obtained health information relating to bioterrorism and/or anthrax during late 2001 (Appendix 1). The survey was an original design and not based on any previously existing surveys. The survey was written in English and professionally translated into Spanish. A consent form explaining the study and any possible risks to subjects was also written in English and professionally translated into Spanish. The survey was pre-tested with a small sample of patients from an outpatient clinic at the Brigham and Women's Hospital and changes to the survey were made according to patient suggestions and reactions.

Five hundred patients were randomly selected to participate in this study. Patients were selected from the patient panels of two ambulatory primary care clinics affiliated with the Brigham and Women's Hospital in Boston, Massachusetts. Only patients who were over 18 years of age and who spoke English and/or Spanish were eligible for selection for the study. In August 2002, surveys and consent forms were mailed to the randomly selected patients. Opt-out cards were also included in the mailing so that patients could decline participation if desired. A Spanish translation of the mailing was sent to those identified as primarily Spanish speaking. In the following six months, three subsequent mailings were sent to those who did not respond to the survey. Respondents were compensated for their time and effort with a $10.00 voucher. In an effort to increase the response rate, non-respondents were telephoned after the final mailing and asked if they would be willing to complete the survey.

Descriptive analyses were performed on the survey results using SAS and Excel. Chi-squared analyses were used to compare survey respondents to the overall clinic population, and to compare those who searched the Internet for information on anthrax and bioterrorism with those who did not. Results are shown as percentages with 95% confidence intervals.

Results

We received 209 completed surveys for a response rate of 42%. The population of survey respondents differed significantly from the overall clinic population in the demographic categories of race (p<0.001) and age (p<0.001), but not gender (p=0.08); the population of survey respondents contained a greater percentage of white and middle-aged patients than the overall clinic population. More respondents self-identified as white than as any other category (Table 1). More reported an annual household income of greater than $75,000 than any other category, although the remaining respondents were relatively evenly distributed throughout the other income categories. Just over half were college-educated. The majority of survey respondents reported good or excellent health.

Table 1. Demographic information on survey respondents

Demographic	Count	Percentage
Sex		
Female	117	56%
Male	89	43%
Unknown	3	1%
Education Level		
Did not graduate from high school	30	14%
Graduated from high school or GED	25	12%
Some college education or 2-year degree	37	18%
College degree or more	108	52%
Unknown	9	4%
Race		
Caucasian	137	66%
Black or African American	17	8%
Asian	9	4%
Native American or Alaskan	3	1%
Other	33	16%
Unknown	10	5%
Annual Household Income		
Less than $10,000	25	13%
$10,000 - $24,999	21	11%
$25,000 - $34,999	28	14%
$35,000 - $49,999	33	17%
$50,000 - $74,999	27	14%
Over $75,000	64	32%

The survey data suggest that respondents were relatively sophisticated regarding computer use. Eighty-six percent (95% CI, 81% - 91%) used computers. Ninety-six percent (95% CI, 93% - 99%) had access to the Internet, and 86% (95% CI, 81% - 91%) had been using the Internet for 2 years or more.

The 15% (95% CI, 10% - 20%) of respondents who reported that their health was "fair" or "poor" reported less computer use and access than the overall surveyed population. Thirty-eight percent (95% CI, 21% - 55%) of those in fair or poor health reported not using a computer at all. Only 63% (95% CI, 46% - 80%) of those in fair or poor health had Internet access, and only 28% (95% CI, 12% - 44%) had used the Internet for two years or more.

Respondents trusted health information from their physicians more than health information from other sources. Health websites were the next most trusted source, and were slightly more trusted than public radioand newspapers, and much more trusted than online newspaper sites, other online news sources, TV shows and news reports, magazines, other people, and other radio sources (Figure 1).

During late 2001, respondents received very little information on anthrax and/or bioterrorism from physicians, reportedly the most trusted source of information. Only 4% (95% CI, 1% - 7%) of respondents reported that their physician gave them information about anthrax in person. However, extrapolating from the proportion of patients expected to have had office visits during this time, it is possible that up to 12% of patients seeing their physicians received information about anthrax. Just 1% (95% CI, 0% - 2%) said that their physician sent them information on anthrax through the postal mail. Only one respondent (< 1%) reported receiving an e-mail from their physician with information on anthrax.

Only 12% (95% CI, 7% - 17%) reported that they obtained "a lot" of information from health websites, the next most-trusted source after physicians. Despite television shows and news reports being reported as the least trusted source of information, more people (51% (95% CI, 44% - 58%) reported receiving "a lot" of information about anthrax and bioterrorism from this source than from any other source.

Figure 1. Percentage of survey respondents reporting they trust various forms of communication either "a lot" or "completely"
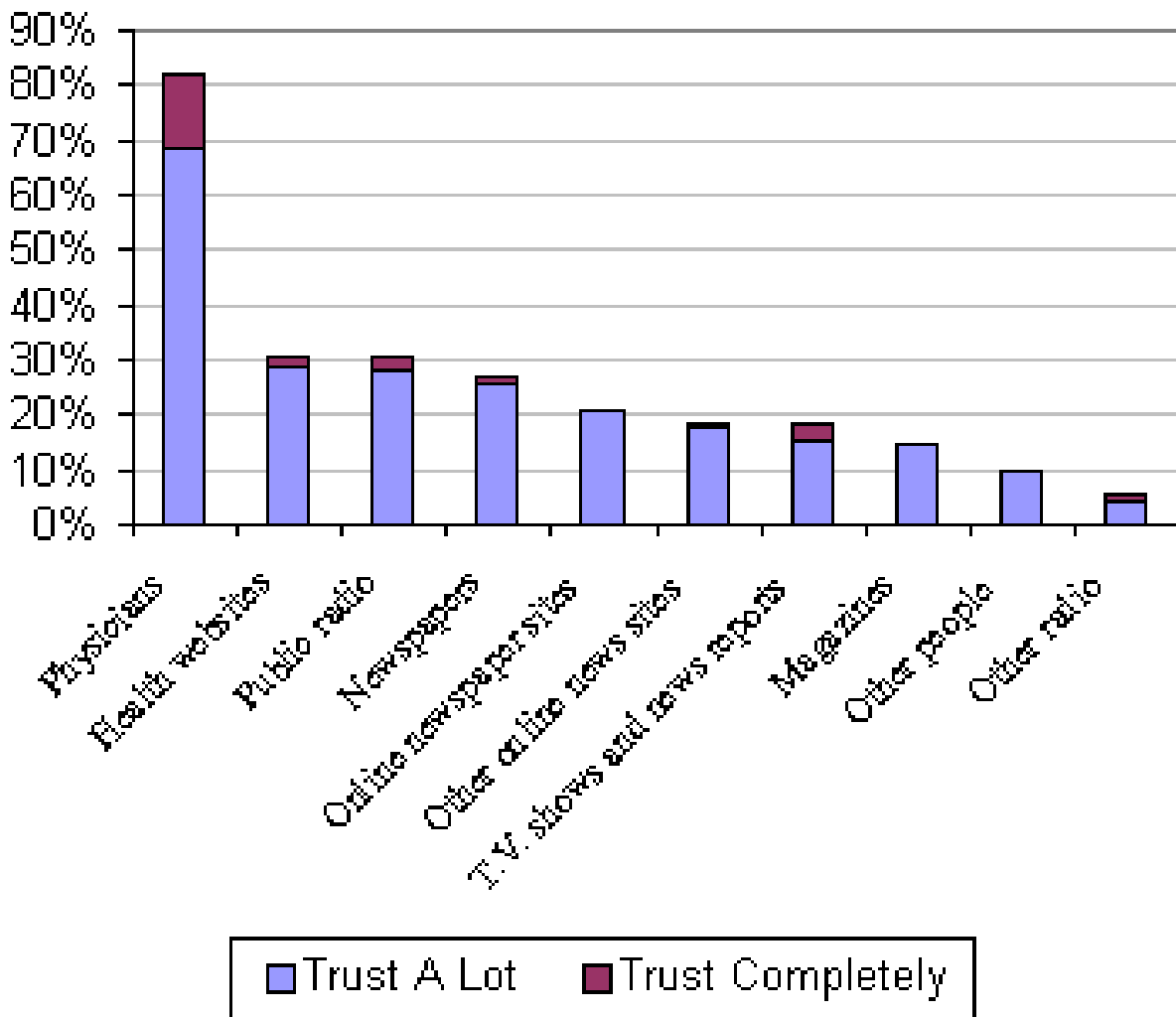
Sixteen percent of respondents (95% CI, 10% - 22%) said that as a result of September 11th and the anthrax scare, their overall use of the Internet increased between September and December of 2001. Twenty-one percent (95% CI, 15% - 27%) of respondents reported searching the Internet for information on bioterrorism and/or anthrax during late 2001. This group reflected a population that tended to be more educated and wealthier than the overall surveyed population, with a greater proportion of White (Table 2). Of those who searched the Internet for information on bioterrorism and/or anthrax, 54% (95% CI, 41% - 67%) reported that they did so because they wanted more information than they were getting from other sources. In addition, 63% (95% CI, 54% - 72%) of searchers turned to the Internet for information on the risk of catching anthrax and/or on how to protect oneself from anthrax exposure. Eighty-eight percent (95% CI, 79% - 97%) of searchers reported that they did not get any advice on where to search for information on anthrax and/or bioterrorism. Sixty-five percent (95% CI, 53% - 77%) located their information by searching for the word "anthrax" or "bioterrorism". Forty percent (95% CI, 27% - 53%) obtained their Internet information from online newspapers, 25% (95% CI, 14% - 36%) from private health websites like WebMD or Medscape, and 26% (95% CI, 14% - 38%) from public health websites like www.cdc.gov (Centers for Disease Control).

Those who searched the Internet tended to be white, female, and well-educated, although statistical analyses did not reveal any statistically significant differences in the demographic profiles of those who searched the Internet and those who did not. Note that seven survey respondents did not provide information regarding whether they searched the Internet for information on anthrax and bioterrorism, and these seven respondents are excluded from this table.

Internet information had an effect on the behavior of those who searched for such information. Of the respondents who reported searching online for information relating to anthrax and/or bioterrorism, 58% (95% CI, 44% - 72%) reported that they handled mail differently as a result, and 65% (95% CI, 52%-78%) reported that they washed their hands more often as a result of such information.

Table 2. Demographic information on survey respondents who searched the Internet for information on anthrax and bioterrorism and survey respondents who did not search the Internet for such information

Demographic	Searchers (n=43)		Non-searchers (n=159)		Significant Difference?
	Count	Percentage	Count	Percentage	
Sex					
Female	28	65%	84	53%	No, p = 0.15
Male	15	35%	72	45%	No, p = 0.22
Unknown	0	0%	3	2%	No, p = 0.36
Race					
Caucasian	31	72%	102	64%	No, p = 0.33
Black	3	7%	13	8%	No, p = 0.80
Asian	4	9%	5	3%	No, p = 0.08
Native American	1	2%	2	1%	No, p = 0.61
Other	4	9%	25	16%	No, p = 0.29
Unknown	0	0	12	8%	
Education Level					
8th Grade or Less	1	2%	13	8%	No, p = 0.18
Some high school	2	5%	11	7%	No, p = 0.59
High school graduate or GED	2	5%	22	14%	No, p = 0.10
Some college or 2-year degree	11	26%	24	15%	No, p = 0.11
4-year college graduate	15	35%	33	21%	No, p = 0.05
More than 4 year college graduate	12	28%	47	29%	No, p = 0.83
Unknown	0	0	9	6%	No, p = 0.11
Annual Household Income					
Less than $10,000	3	7%	20	13%	No, p = 0.30
$10,000-$24,999	4	9%	15	9%	No, p = 0.98
$25,000-$34,999	6	14%	21	13%	No, p = 0.90
$35,000-$49,999	7	16%	25	16%	No, p = 0.93
$50,000-$74,999	8	19%	18	11%	No, p = 0.21
$75,000 +	14	33%	50	31%	No, p = 0.89
Unknown	1	2%	10	6%	No, p = 0.31

Discussion

Public health crises may take the form of bioterrorist attacks or natural outbreaks. In such situations, it is important to quickly convey to an alarmed public not only accurate facts but also constructive advice that people can apply with confidence. Ensuring that individuals are connected to validated information as quickly as possible from sources that will most likely influence behavior positively is a key goal. Because messages from public health authorities are often delivered in the same context as other less credible information, the public is left to sift through a vast array of information to assess the personal risks associated with emerging events. While mass media campaigns through traditional media such as newspapers,

television and radio are clearly influential in shaping individuals' responses to events, the difficulty inherent in assessing the legitimacy of these campaigns may make them less effective in positively affecting behavior. Our survey results suggest that in situations such as the anthrax threat, a portion of the population turns to the Internet to clarify what they may have learned through mass media campaigns or to get more information than was obtained through such campaigns. These people generally do not get advice about where to find the best Internet information, nor do they discuss the information they find with a healthcare provider. However, as hypothesized, the information they find can affect their behavior; a majority of those in our study who searched the Internet for information on the anthrax threat reported that the information they found lead them to wash their hands more often and handle mail differently,

illustrating the potential of the Internet to help manage a public health emergency.

How can those who manage public health crises best realize the potential of the Internet as a communication channel? How can they ensure that accurate and influential information is reaching the greatest number of people as quickly as possible? Considering these questions and given the increased patient demand for e-mail communication with physicians' practices, [8] it is relevant to consider the role that physician-patient e-mail communication may play in shaping the management of public health emergencies. Our data support other research [4,5] that shows physicians are highly trusted sources of information and, as a result, it is logical to consider this trust when strategizing about how to most effectively deliver reliable information to a large population. Physician practices could e-mail their patients accurate information on public health concerns, including links to validated websites such as www.cdc.gov. This approach could use the relationship between the physician and patient to promote a flow of information that is more individualized on the public health issue at hand. Physician advice in this context is likely to be effective, as it is well understood by behavioral scientists that the most effective way to teach or persuade an individual to assess the risks and benefits of a particular course of action is through one-to-one contact [9]. While an e-mail from the practice of a physician is not one-to-one communication, it is certainly more personal than other communication devices such as television and newspaper and thus may be more influential. And with regard to Internet connectivity, almost all survey respondents reported having Internet access from somewhere, with most having it from home, suggesting that in times of public health emergencies authorities and public health officials would be able to reach a large proportion of the population via the web.

Even though the role of primary care physicians as disseminators of health information via e-mail has much potential, physicians identify a number of obstacles to its adoption, [10] such as medical liability risks, work load concerns, and a lack of reimbursement. Public health officials are in the position to distribute relevant information to primary care physicians and/or their staff, who could review such information and forward it to their patients with minimal time and effort. Given the inevitable growth in patient e-mail with health care practices, patient e-mail addresses will become available to practices making it possible to send large, all-patient e-mail distributions.

If during times of public health crises we are better able to facilitate the communication of health risk information and behavioral advice via the Internet through such mechanisms as increased physician-patient e-mail use, not all segments of the population will immediately benefit equally from this development. Those who searched the Internet for information on bioterrorism and/or anthrax during late 2001, tended to report good or excellent health, be Caucasian , and have higher education levels and higher average incomes than the overall surveyed population. Unfortunately, those reporting fair or poor health and who may be at the greatest risk of becoming ill when exposed to infectious disease or bioterrorist agents also reported lower levels of computer use and Internet access. These findings are consistent with previous research suggesting that Internet "connectivity" is directly related to income and is unequally distributed racially and ethnically [11]. Those in fair or poor health, who may be at the greatest risk of becoming ill when exposed to infectious disease or bioterrorist agents, may not have high levels of Internet connectivity. Those survey respondents who reported fair or poor health also reported lower levels of computer use and Internet access. Given this trend, it is likely that those who used the Internet as an information source during the anthrax threats did not belong to a more vulnerable group of people with underlying health issues. More research is necessary to determine how to best bridge these "digital divides" in terms of health status, race, ethnicity, and income, especially given the Internet's potential to positively influence behavior in times of public health emergencies. Those with less "connectivity" may become even more vulnerable if they are unable to access reliable information regarding how to best protect oneself during an outbreak or bioterrorist attack.

This study has several limitations. First, it was conducted with patients drawn from only two clinics in the Boston area, and the surveyed population may not be representative of the population in other areas of the US or in other countries. Importantly, the surveyed population may represent a more "wired" group than the overall US population; in our study, 96% of respondents reported Internet access, whereas only 62% of the overall US population are estimated to have Internet access [12]. Also, the survey was conducted almost a year after the anthrax scare. It is possible that respondents might have answered certain questions differently had the events surrounding the anthrax scare been more recent. Additionally, the survey had a relatively low response rate, and the population of survey respondents contained a significantly greater proportion of middle-aged Caucasians than the overall clinic population from which study participants were selected.

In conclusion, the Internet has changed the way we live, work, and communicate with each other, and it is likely to become an important part of how public health and medical professionals communicate with the public. In this context, it is important to strategize about how to best convey accurate, trustworthy, and influential information regarding health risks and advice via this communication channel. These issues are especially salient when considering times of public alarm due to bioterrorist threats or other outbreaks of infectious disease, such as the situation we recently witnessed with SARS. Although the challenge of achieving equitable Internet access for all demographic groups remains, our results suggest that information obtained from trustworthy sources on the web may be effective in positively influencing the behavior of the public during public health crises. If, in addition, public health authorities provided physician practices with validated and targeted information on emerging events that could then be e-mailed to patients, this more individualized approach could provide an additional lever with which to elicit appropriate responses from the public.

Conflicts of Interest

None declared.

Multimedia Appendix

Downloadable WinWord file of the English version of the survey instrument used in this study. A professional Spanish translation was mailed to patients identified as Spanish speaking: [DOC File, 136KB - jmir_v6i1e8_app1.doc]

References

1. Gray GM, Ropeik DP. Dealing with the dangers of fear: the role of risk communication. Health Aff (Millwood) 2002;21(6):106-116. [Medline: 22330010] [doi: 10.1377/hlthaff.21.6.106]
2. Hobbs J, Kittler AF, Fox S, Middleton B, Bates DW. Communicating health information to an alarmed public facing a threat such as a bioterrorist attack. J Health Comm 2004 [in press].
3. Americans trust physicians, not government, with medical info. Manag Care Strateg 1997 Oct;5(10):119-120. [Medline: 10173335]
4. Jones JA, Kreps GL. Communicating With Your Doctor: Getting the Most Out of Health Care (Hampton Press Communication Series). Cresskill, NJ: Hampton Press, Incorporated; May 1, 1995.
5. New American Academy of Dermatology survey finds patients do their homework. 2002. URL: http://www.aad.org/PressReleases/homework.html [accessed 2004 Feb 24]
6. Fox S, Fallows D. Internet Health Resources. Pew Internet and American Life Project. 2003 Jul 16. URL: http://www.pewinternet.org/reports/toc.asp?Report=95 [accessed 2003 Nov 3]
7. The Internet life report: tracking online life. Pew Internet and American Life Project. 2000 May 10. URL: http://www.pewinternet.org/reports/toc.asp?Report=11 [accessed 2003 Nov 3]
8. ; Harris Interactive. Patient/physician online communication: many patients want it, would pay for it, and it would influence their choice of doctors and health plans. Health Care News 2002 Apr;2(8):1-3 [FREE Full text]
9. Rodgers JE. Introduction of section: overarching considerations in risk communications: romancing the message. J Natl Cancer Inst Monogr 1999(25):21-22. [Medline: 20314204]
10. Hobbs J, Wald J, Jagannath YS, Kittler A, Pizziferri L, Volk LA, et al. Opportunities to enhance patient and physician e-mail contact. Int J Med Inform 2003 Apr;70(1):1-9. [Medline: 22593109] [doi: 10.1016/S1386-5056(03)00007-8]
11. Mandl KD, Katz SB, Kohane IS. Social equity and access to the World Wide Web and E-mail: implications for design and implementation of medical applications. Proc AMIA Symp 1998:215-219. [Medline: 99123118]
12. Pew Internet & American Life Project Survey. 2003 Jun. URL: http://www.pewinternet.org/reports/pdfs/PIP_Spam_Topline.pdf [accessed 2003 Nov 3]

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Original Paper

Experience and Attitudes towards Information Technology among First-Year Medical Students in Denmark: Longitudinal Questionnaire Survey

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Abstract

Background: As more and more information technology (IT) resources become available both for support of campus- based medical education and for Web-based learning, it becomes increasingly interesting to map the information technology resources available to medical students and the attitudes students have towards their use.

Objective: To determine how extensively and effectively information handling skills are being taught in the medical curriculum, the study investigated Internet and computer availability and usage, and attitudes towards information technology among first-year medical students in Aarhus, Denmark, during a five-year period.

Methods: In the period from 1998 to 2002, students beginning the first semester of medical school were given courses on effective use of IT in their studies. As a part of the tutorials, the students were asked to complete a web-based questionnaire which included questions related to IT readiness and attitudes towards using IT in studies.

Results: A total of 1159 students (78%) responded. Overall, 71.7% of the respondents indicating they had access to a computer at home, a number that did not change significantly during the study period. Over time, the power of students' computers and the use of e-mail and Internet did increase significantly. By fall 2002, approximately 90% of students used e-mail regularly, 80% used the Internet regularly, and 60% had access to the Internet from home. Significantly more males than females had access to a computer at home, and males had a more positive attitude towards the use of computers in their medical studies. A fairly constant number of students (3-7%) stated that they would prefer not to have to use computers in their studies.

Conclusions: Taken together with our experience from classroom teaching, these results indicate optional teaching of basic information technology still needs to be integrated into medical studies, and that this need does not seem likely to disappear in the near future.

Introduction

Software for computer-assisted learning (CAL) in medicine has been available from the 1960s, or almost as long as computers. Results of evaluations of software for teaching and learning in medicine vary considerably, largely because of differences in the learning situations and in the evaluation design [1-5]. In spite of the early awareness of the potential of CAL programs among dedicated educators, production and marketing of a substantial amount of programs started only after the multimedia computer became readily available in the mid-1990s.

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With the increased availability and speed of the Internet come new ways of disseminating interactive multimedia learning modules and possibilities for integrating information and communication technologies into other methods of teaching and learning.

The approach of many teachers and course directors in traditional universities has been to "wait and see." A growing number of enthusiasts, however, have tried to implement new ways of teaching and learning using, or facilitated by, information technology (IT), and in many cases integration of information and communication technology (ICT) has been used to support changes in teaching and learning methods.

The approach of students, whose motivation is usually exams, could also be characterized as "wait and see." The question is how long to wait and then what to look for. Access to computers, at home and on campus, and Internet access are both important. The issue of students' IT literacy, however, may be even more important. It is often thought that it is only a matter of time until all young students become skilful in the use of computers, and IT training is no longer necessary in higher education. The present study was conducted to test this hypothesis and to determine whether students entering medical school already had all the IT skills they would need to use IT effectively during their medical studies. Analysing IT skills is especially difficult when comparing results over a span of years: what would be seen as a trivial task today may have required advanced knowledge five years ago. Consequently, instead of skills, the study investigated computer availability and attitudes and how these measures might be interrelated. Several previous studies have addressed the issue of IT literacy among medical students, typically through questionnaires given in one or a few semesters [6- 14]. The present study, extending from the 1998 fall semester to the 2002 fall semester, revealed developments over a five-year period that was characterized by an unforeseen expansion in IT and Internet availability throughout the Western world.

We asked medical students about their access to IT, their attitudes and interests in using IT as part of the medical studies they had just started. The purpose was to clarify when and where IT could be effectively integrated and what IT training and hardware needs could be expected.

Methods

In the period from 1998 to 2002 (nine semesters), students beginning the first semester of medical school in Aarhus, Denmark, were given two lectures and three group-based tutorials on effective use of IT in their studies. As a part of the tutorials, the students were asked to complete a questionnaire (seAppendix 1). This Web-based questionnaire was completed 2 to 3 weeks after start of studies, and included questions related to IT readiness and attitudes towards using IT in studies. The questionnaire was set up using Coldfusion [15] on a Windows 2000 www-server. Data were entered into an open database connectivity (ODBC) database and were analysed using Microsoft Excel. Teachers were present during the input phase to answer technical questions.

The students were asked their age and sex; whether they had access to a computer at home and whether it was PC, Macintosh, or other; which operating system it used; the amount of RAM; the processor type; and whether the computer had a soundcard, a CD drive, or a modem attached. Students were also asked whether they had access to the Internet and e-mail from home, and the frequency of usage. Finally, the students were asked the following questions about their attitudes towards IT in the medical school.

1. Would you like to use the computer for calculations and reports?
2. Would you like to use the computer as a supplement to teaching?
3. Would you like to use the computer as a replacement for some of the theoretical teaching?
4. Would you like to be able to ask questions to teachers via e-mail?
5. Would you like to be able to use the computer for distance learning from home?
6. Would you prefer that you *did not* have to use the computer during your medical studies?

Minor additions to answering options were made as new processors and operating systems became available.

The X^2 test was used to compare frequencies.

Results

Basic data

Of 1474 medical students who started their studies between fall 1998 and fall 2002, 1159 (78.6%) completed the Web-based questionnaire. The average age was 21.6 years (Figure 1b). Students beginning in the summer were, on average, 2 years older than those beginning in winter, which is a result of the way students are accepted for medical studies in Aarhus. Of all participating students, 60.3% were female. Distributions for semesters are given in Figure 1a and Figure 1b. A total of 71.7% of all students (79.7% of males; 67.5% of females) indicated they had access to a computer at home. There were substantial fluctuations from semester to semester (Figure 1c), but comparing the average of the first four semesters with the average of the last four revealed only a slight increase from 70.9% to 73.1% (NS). The increase from 70.4% in fall 1998 to 79.3% in 2002 was not statistically significant. Internet access from home increased from 20.4% to 62.9% (p < 0.001) in the study period, and there was an even more pronounced increase in the use, from any location, of Internet and e-mail (Figure 1e and Figure 1f). It is especially significant that, although the university did not require the students to use e-mail, by the end of the study period, 88.7% of all students used e-mail regularly.

Figure 1. Distribution of age and gender (a, b) and computer, Internet, and e-mail usage (c to f). Spring semesters are indicated with *1*; fall semesters with *2*. Use of Internet and e-mail was graded as never, rarely, regularly, often, or daily. The curves sum up answers: regularly, often, and daily

Computers used

Not surprisingly, the power of computers increased in the study period (Figure 2a). The incidence of soundcards in computers available to students increased from 48% to 71% (p < 0.001), the incidence of CD drives in home computers increased from 52% to 76% (p < 0.001), and of modems from 27% to 59% (p < 0.001).

Among medical students in Denmark, Macintosh computers are not in common use. Numbers decreased from about 3 to 4% at the start of the study period to about 0 to 1% in the last part (Figure 2b).

Attitudes

Males were significantly (p < 0.001) more interested in replacing traditional with ICT- supported teaching and learning. An

average of 46.6% of males versus 21.8% of females indicated that they would like to replace traditional teaching with use of computers if possible. Despite fluctuations, there was no trend towards a consistent change in these numbers during the study period (Figure 2c).

A small percentage (6.8% of females and 3.3% of males) indicated that they would prefer not to have to use a computer during their medical studies. Again, in spite of fluctuations, there was no trend towards a consistent change in this number (Figure 2d).

The difference between males and females in attitudes towards use of distance education was also highly significant ($p < 0.001$): 38.7% of males versus 19.9% of females indicated a positive attitude (Figure 2e).

The attitude towards use of ICT resources as a supplement was more positive than for ICT replacement or for distance education (86% of boys and 76% of girls were positive, Figure 2f)

Figure 2. Type of computer (a, b) and attitudes towards use of computer (c to f). Spring semesters are indicated with *1*; fall semesters with *2*. As might be expected, the number of powerful computers among students was increasing; The percentage of Macintosh computers was decreasing. 6.8% of females answered that they would rather not use a computer as part of the study. The corresponding percentage for males was 3.3%

Discussion

Use of IT as a tool to support medical teaching and learning was introduced gradually over several years at The University of Aarhus, without a well-defined strategy. Similar trends have been reported from many other universities. One reason may be the great diversity of IT skills among both teachers and students. There may also be a general reluctance to change educational methods and a belief that available IT resources would not enhance learning. Many things changed during the period of this study. Many medical schools have moved towards problem-based learning. Implementation of computer-supported collaborative learning [16] has driven IT investments and implementation in some schools, and certainly the value of available Internet resources and of e-communication in supporting medical learning can no longer be denied. At the University of Aarhus, which is a typical research-intensive institution, educational methods have undergone an evolution rather that a revolution and IT has not been considered a driving force for pedagogical change. Still, project work and other study areas that rely heavily on medical literature available through the Web have demonstrated the need for a minimum of IT literacy among the students, and it is important to know roughly the number of students in need of special IT courses.

This study shows that an average of 71.7% of new medical students had access to a computer at home. The number was significantly higher among males, and showed considerable fluctuations from semester to semester, but did not increase significantly in the study period (between 1998 and 2002). When compared to German study from 1992 by Gunther Eysenbach, however, this study shows a significant increase in IT availability and knowledge [17].

Approximately 79% of registered students completed the questionnaire. The seminar included a number of important practical issues, such as a general introduction to the use of the university's IT facilities. We encouraged all participants in the seminars to complete the survey, but did not record reasons for not completing it. In principle, the 21% of registered students who did not complete the questionnaire might have different attitudes towards IT and their access to computers at home might differ from those who completed the survey. If this was the case, absolute numbers might be slightly biased. We do, however, assume that failure to complete the survey would be fairly constant during the study period, and thus relative developments with time would be unaffected by the missing questionnaires.

As noted, students beginning medical studies in the summer were an average of 2 years older than those beginning in the winter. A comparison of computer availability with age, revealed a U-shaped curve: ~80% at 19 years, ~60% at 22 years, and ~88% at 26 years. Changes in computer availability during the study period therefore can probably be attributed, at least in part, to fluctuations in age. Fluctuations in the percentage of females accepted could also be expected to influence computer availability over years. A comparison of Figure 1b and Figure 1c, however, does not show a consistent trend.

The most comprehensive study of IT literacy conducted in European universities is probably the Survey of European Universities Skills in ICT of Students and Staff (SEUSISS) project, funded under the EU-Socrates Minerva Programme. The consortium, which includes seven universities from the UK, Finland, Norway, The Netherlands, Italy, France, and Spain, gathered data in 2001 and 2002 in a continuation of a 10-year University of Edinburgh data collection project [18,19,20]. Although the present study included only medical students, many of the questions related to IT literacy can be expected to apply to all students in higher education, with the exception of students in computer science and related areas.

Questions that remain important in the present study and in the SEUSISS and Edinburgh studies are:

- What are the developments in *general IT literacy*, computer availability at home, and general availability to IT, and can we expect that problems with IT literacy will disappear with time?
- Can university teachers and administrators expect that *e-communication* will reach all students?
- Are *gender differences* in IT attitudes and literacy significant and do these differences tend to change over time?

General IT literacy

Roughly half of all students had access to a home-PC with a CD, soundcard, and sufficient computing power and RAM to effectively run modern multimedia applications. Whereas access to *any* PC at home showed only a very small increase, access to a "modern multimedia PC" increased from about 30% to about 65%. In the SEUSISS project (2001-2002), the numbers for PC ownership at the start of studies varied from 54% (Åbo, Finland) to 89% (Groningen, the Netherlands). In Edinburgh by 2000, ownership was at 44% for males and 37% for females, and the Edinburgh study reports that this gender gap diminished with time. The data from this study seem to be consistent with the other European data, although the gender differences in this study did not decrease, and no distinction was made in this study between ownership and availability of IT at home. Availability of a powerful PC at home is increasing, but a substantial proportion of new students still do not have access to a computer at home, and it is still too early to predict that they will within the next few years.

The Edinburgh study reports about 8% Macintosh users, and a slight trend towards more Macintosh users among women. Medical students, like most other computer users in Denmark, use PCs almost exclusively.

It is one thing is to own a PC or to have access to one, quite another is to possess IT skills and to be IT literate. A dramatic increase in IT literacy might be expected during these years when IT and Internet use have increased generally. Data on Internet availability are continuously monitored by the European Union, and their data show that Denmark is one of the three leading countries with respect to IT use and Internet spread [21].

In the present study, direct measures of IT-literacy were not identified, and no attempt was made to test the students in this respect. However, it seems reasonable to expect a correlation

between attitudes towards IT and IT literacy. Indeed in hands-on courses a small percentage of students were found to be absolute novices with respect to computer use. Between 3 and 7% of the students (significantly more females than males) who indicated that they would prefer not to have to use computers in their studies. The consistency of this finding, corroborated in several earlier studies [7,8,9,14,18], suggests there is a need for training in basic IT and information-handling skills as an optional element in medical training [22]. Moreover, this study does not suggest this need is likely to disappear in the near future.

E-communication

Use of Internet and e-mail increased dramatically during the study period. The curve for e-mail, in approaching 100%, shows a decreasing slope, while the curve for Internet use indicates that a further increase above 80% can be expected. An interesting question is whether these numbers will increase to 100%. At present, the university does not use e-mail and Internet as a mandatory route of communication with or among medical students, but the numbers presented here indicate that the time may be ripe to start doing so. Several universities around the world have successfully started using e-mail as a mandatory communication, and the Internet as a mandatory information and communication channel. Although a small number of students and teachers may experience going from paper-based to e-communication as a drastic step, this study shows that it will probably not be a problem for the vast majority, and that the minority will meet only temporary difficulties.

Gender differences

This study has revealed significant gender differences both in access to computers and in readiness to integrate IT in the learning process. As an example, roughly 50% of males versus 25% of females responded that they would like to replace some traditional teaching with IT-based activities.

In these respects, the study correlates directly with the 10 year follow-up study from Edinburgh [18,19]. The results are interesting in a number of ways when it comes to planning, developing, and implementing ICT-supported learning activities. Communications with the medical students indicate that most female students are not directly opposed to ICT-supported teaching and learning; however, female students may be more pragmatic and more focused on exams, whereas some male students may favour the freedom of time and space offered by e-learning.

Conclusions

During the five years of this study there was a dramatic increase in availability of IT resources. It can be considered positive when about 30% of students indicated that they would like to exchange traditional learning for e-learning, and about 80% indicated that would like to use ICT resources as a supplement. Some course directors and teachers are still reluctant to increase the importance of IT support in the studies, but this study indicates that most students are ready to change. There is still a need for teaching in basic IT as part of medical study, and this need does not seem likely to disappear in the near future.

Conflicts of Interest

None declared.

Multimedia Appendix

Web-based Questionnaire: [HTML File, 20KB - jmir_v6i1e10_app1.html]

References

1. Atkins, O'Halloran. Evaluating multimedia applications for medical education. In: AMEE Guide No 6: Association for Medical Education in Europe; 1995. URL: http://www.amee.org/%5BAMEE%5D

2. Alexander S, McKenzie J. An evaluation of information technology projects for university learning. In: AMEE Guide No 6. Canberra: CUTSD, Commonwealth of Australia; 1998. URL: http://www.dest.gov.au/archive/cutsd/publications/%5BCUTSD%5D

3. Hovenga EJ. Using multi media to enhance a flexible learning program: lessons learned. Proc AMIA Symp 1999:530-534 [FREE Full text] [Medline: 20032925]

4. Brady Boyce Ba, Winne MD. Developing an evaluation tool for instructional software programs. Nurse Educ 2000 May;25(3):145-148. [Medline: 11111571] [doi: 10.1097/00006223-200005000-00015]

5. Dørup J. Educational technology as a scientific discipline. In: Haux R, Kulikowski C, editors. Yearbook of Medical Informatics. Stuttgart: IMIA; 2002:533-535 URL: http://www.dest.gov.au/archive/cutsd/publications/%5BCUTSD%5D

6. Bresnitz EA, Stettin GD, Gabrielson IW. A survey of computer literacy among medical students. J Med Educ 1986 May;61(5):410-412. [Medline: 86200102]

7. Crowe P, Howie C, Thorpe M. Self-reported computer literacy of medical students and staff: good facilities are not enough. Med Teach 1998;20(3):264-265 [FREE Full text] [doi: 10.1080/01421599881057]

8. Gouveia-oliveira A, Rodrigues T, De Melo FG. Computer education: attitudes and opinions of first-year medical students. Med Educ 1994 Nov;28(6):501-507. [Medline: 95166065]

9. Jones RB, Navin LM, Barrie J, Hillan E, Kinane D. Computer literacy among medical, nursing, dental and veterinary undergraduates. Med Educ 1991 May;25(3):191-195. [Medline: 91312228]

10.   Koschmann T. Medical education and computer literacy: learning about, through, and with computers. Acad Med 1995 Sep;70(9):818-821. [Medline: 95398748]

11.   Nurjahan MI, Lim TA, Foong A, Yeong SW, Ware J. Computer literacy in medical students. Med Educ 2000 Nov;34(11):966. [Medline: 20561287] [doi: 10.1046/j.1365-2923.2000.0818i.x]

12.   Sancho JJ, González JC, Patak A, Sanz F, Sitges-serra A. Introducing medical students to medical informatics. Med Educ 1993 Nov;27(6):479-483. [Medline: 94268339]

13.   Stringer J, Moreno EA. A computer literacy requirement for medical students. Acad Med 1996 May;71(5):522. [Medline: 20140661]

14.   Peroz I, Bösel C, Lange KP. Representative survey of dental students about the present state of education, PC equipment and configuration requirements for a net-based dental education system. Med Teach 2003 Jul;25(4):385-390. [Medline: 22775696] [doi: 10.1080/0142159031000136761]

15.   ; Macromedia. Macromedia.com. URL: http://www.macromedia.com/ [accessed 2004 March 5]

16.   Kumar VS. Computer-supported collaborative learning: issues for research. URL: http://www.cs.usask.ca/grads/vsk719/academic/890/project2/project2.html [accessed 2004 March 5]

17.   Eysenbach G. Computereinsatz und Computerkenntnisse unter Medizinstudenten [Computer use and computer literacy among medical students]. Informatik, Biometrie und Epidemiologie in Medizin und Biologie 1995;26(1):56-66 [FREE Full text]

18.   Asgari-jirhandeh N, Haywood J. Computer awareness among medical students: a survey. Med Educ 1997 May;31(3):225-229. [Medline: 97374694]

19.   Macleod H, Haywood D, Anderson C. Gender & ICT-a 10-year study of new undergraduates. URL: http://homepages.ed.ac.uk/jhaywood/papers/techtrends.pdf [accessed 2004 March 5]

20.   Survey of European Universities Skills in ICT of Students and Staff. URL: http://www.intermedia.uib.no/seusiss/results.html [accessed 2004 March 5]

21.   Europa: European Information Society. URL: http://www.europa.eu.int/information_society/eeurope/2002/benchmarking/list/2001/index_en.htm [accessed 2004 March 5]

22.   Dørup J, Schacht Hansen M, Ribe LR. Integrating IT-supported and traditional learning in a Health Informatics course. In: Ribeiro LM, Marques dos Santos J, editors. Proceedings of the 8th International EUIS Conference. Porto; Jun 19, 2002:106-107 URL: http://www.intermed.dk/contentmanagement/itfacilitation.pdf [accessed 2004 March 5]

Abbreviations

CAL: computer assisted learning
EU: European Union
IT: information technology
ICT: information and communication technology
ODBC: open database connectivity
RAM: random access memory
SEUSISS: Survey of European Universities Skills in ICT of Students and Staff

Original Paper

Online Pediatric Information Seeking Among Mothers of Young Children: Results From a Qualitative Study Using Focus Groups

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Abstract

Background: Pre-natal and post-natal periods are times when many women actively seek health information from multiple sources, including the Internet. However, little is known about how pregnant women and mothers of young children seek and process online pediatric health information.

Objective: To explore why and where mothers of young children look for online health information and how they determine if the information they receive is trustworthy.

Methods: Focus groups were conducted in a Southeastern US city to provide an in-depth exploration of web-related behaviors and beliefs among mothers who work inside and outside of the home. Data from the focus groups were coded using deductive and inductive coding schemes and content was analyzed for the existence of themes.

Results: Twenty mothers of young children participated in four focus groups. Most participants sought information on the Internet during pregnancy and nearly all sought online information after their child was born, primarily to diagnose or treat pediatric conditions and to seek advice on parenting and development. Participants mainly used commercial information websites for health information and many expressed disdain for commercial product websites. Many also expressed concerns about the reliability of health information on the web and described strategies for determining how much they trust each website.

Conclusions: Women appear to be high information seekers during pregnancy and the first few years following delivery, and this period represents an important window of time for providing online health information. Participants suggested that online information sources and motives for providing online information should be clear in order to increase perceptions of trust. Participants expressed preference for online clinical health information that is presented by clinical professionals, and online parenting advice that is presented from other parents.

Introduction

Pregnant women and mothers of young children are active consumers of health information about themselves and their children, and there are countless books, magazines, videos, television programs, classes, and other resources on childbirth, parenting, and pediatrics from which mothers and mothers-to-be can choose. An additional mass communication channel, the World Wide Web, has grown into a popular destination for women seeking health information on a wide range of pediatric topics.

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The proliferation of websites offering pediatric health information is consistent with the growth of the broader universe of health information now available on the Internet. There are thought to be hundreds of thousands of health-related websites [1] and health information is one of the most researched topics among Internet users, [2] particularly among parents [3]. However, the high quantity of health related websites should not be confused with quality. Many studies have found that misleading and even patently false health information is rampant online [4-6]. Previous research with Internet users has found that most health-related searches start in general search engines and that numerous criteria, including many non-scientific judgments, are used by information seekers to assess the credibility of health-related websites [7]. However, little is known about Internet use among mothers of young children, how they use the web to retrieve pediatric health information, and how they make decisions about the veracity of the health information they receive.

The objective of this study was to explore web use preferences and perceptions among mothers of young children. Specifically, *why* they turn to the web for pediatric health information, *where* they go on the web for pediatric health information, and *how* they determine if the pediatric health information they receive online is trustworthy.

Methods

Design and Sample

This study was conducted in early 2001, in a medium-size metropolitan area in the Southeastern US with women recruited from three locations. Two of the locations were day-care facilities: one was affiliated with a governmental office and one was a private day-care facility. Both of these facilities provided full-time daycare and the mothers who were recruited through them held jobs for pay outside of the home. The third location from which women were recruited was a local "mother's center" frequented by mothers who mostly did not hold jobs outside of the home. Eligibility criteria included being at least 18 years of age, having at least one child younger than five, and using the Internet at least once in the previous 6 months.

Four focus groups were conducted: two groups with mothers who worked for pay outside the home and two groups with mothers who did not work outside the home at all, or who did so only part time. The focus groups were separated by participant work status so that mothers in each group would more freely share their experiences and perspectives. In addition, work status may affect people's Internet access and time available for going online. Although seven or eight women were recruited for each group, exactly five women participated in each. Additional focus groups were not conducted after convergence was found in the data across the four groups around the central research questions. Each focus group lasted about 90 minutes and study participants each received a $15 honorarium and complimentary childcare for their children during the focus groups. The study was approved by the Institutional Review Board at the host university and all participants provided written informed consent prior to participating.

Measures

The focus groups were facilitated using a moderator guide that was developed using the "funnel approach" by beginning each discussion with less structured interview questions and moving to more focused questions and probes as the discussion continued [8]. The moderator guide was a female in her mid-20's, with extensive maternal and child health experience. The facilitator used standard focus group moderator guidelines [9] , and the topics that were covered included patterns of Internet use, processes for searching, preferences for types of pediatric health information on the Internet, and perceptions of the trustworthiness of health information sources. In addition to the open-ended questions and follow-up probes in the moderator guide, examples of websites that provide health information about pediatric sun protection were projected onto a screen and questions were asked about the participants' impressions and reactions to these sites. Please refer to the supplemental "Focus Group Guide" available online.

Analysis

All data were collected prior to analysis. The focus group discussions were audiotaped, videotaped and transcribed verbatim, and a research assistant took detailed field notes during each discussion. The videotapes were used to assist with the assignment of specific participant speakers to the transcribed data. After each focus group, the research assistant and the moderator reviewed the field notes and came to consensus on the themes, issues, and ideas presented in the session. The coding scheme then was developed both inductively using a "cut and paste" technique with each research question [9] and deductively using relevant constructs from McGuire's Input/Output Matrix [10] as codes. The McGuire Matrix demonstrates the relationship between message factors or "inputs" (e.g., source, channel, receiver) and the resulting steps of receiving and processing messages or "outputs" (e.g., attention, liking, attitude change). The Ethnograph, [11] a qualitative data analysis program, was used for coding the data and facilitating analysis by generating code-specific reports from the data which were content analyzed for the existence of patterns and themes.

Results

Participants

A total of 20 women, ranging in age from 22 - 42 years, participated in the focus groups. The mean age was 34.5 (S.D.=4.95). Seventeen of the participants were Caucasian, two were African American, and one was Asian American. In addition, half of the participants had one child, eight participants had two children, and two participants had three or more children. Eighteen (90%) of the participants reported having Internet access at home and 80% of the mothers from the groups that worked outside the home reported having Internet access at work.

Reasons for seeking pediatric health information

Almost all participants reported that during their pregnancy they had sought out information on the Internet about many pregnancy-related topics, and this was especially true for first

pregnancies. Of particular interest to the mothers were websites that presented information on fetal development with content that was individually tailored to their due date or stage of pregnancy. Many participants also reported that they sought social support on the web from other pregnant women or mothers, especially during their first pregnancy. For example, one woman stated that "...I was so scared and I would go to this web site every day and just look at it (for) like ten minutes straight and I just found so much helpful information on it (about) being scared and not knowing what to expect." Several participants also shared the fact that they used the Internet to research specific problems they were having with their pregnancy.

The most common reasons that participants reported going online for health information following childbirth included: (1) wanting to learn more about diagnosing and treating specific pediatric health conditions, and (2) seeking out advice and support on parenting issues and development. Nearly every participant reported that she had used the Internet at least once to look up an illness or health condition that her child was experiencing. In many of these cases, the mothers were looking for information to clarify or supplement what they had been told by their doctors and to help them make more informed treatment decisions. For example, one mother whose son had chronic ear infections noted: "...I found so much information about how these things happen, which wasn't explained to me by his doctor. I found that very informative and felt like I knew as much or more than his pediatrician on the subject... And it has been very reassuring to me to know that... if I do a little work I can be much better informed about my children's health."

For addressing more acute health conditions, the findings suggested the presence of two approaches to pediatric information seeking. One group, composed primarily of recent first-time mothers, reported that they regularly turned to the Internet for advice when their child had acute symptoms, when the doctor's office was not as reachable, and when making decisions about going to the emergency room. In contrast, the other group, composed primarily of older mothers, mothers of older children, and those with more than one child, reported that they were more likely to look in books or to call the doctor's answering service than to go online for health information. As one participant noted, "[Reading online pediatric information is] not like having a book. For me, I like having those books at the head of the bed. Because you have your little light on while your spouse is sleeping and you can look at stuff... I still find the computer to be like, yuck. It's not something you can cuddle up with."

Many participants reported turning to the Internet for advice on parenting issues and to seek social support from other mothers. This was particularly common among participants who worked at jobs outside of the home. Several of the working mothers noted that they used the Internet to solicit specific advice or share stories with other mothers, many times with women they only knew over the Internet. As one woman said, "It's nice to have all of that feedback from these other people so that you don't feel like you're alone."

In contrast, many stay-at-home mothers reported that they used the Internet to confirm their beliefs or to reassure themselves that their perceptions were correct. For example, several participants reported that they had looked to the Internet for reassurance that their child's development or behavior was "normal" and some participants sought support online for their ideas about parenting. In some cases, mothers were seeking support for their own beliefs to counter conflicting advice being offered by their pediatrician, and in other cases mothers were seeking a "second opinion" to confirm that advice received from their pediatrician was supported by others, especially other parents. See Table 1 for a list of the key reasons that participants gave for seeking online pediatric information.

Table 1. Reasons that mothers sought pediatric health information

- To learn about diagnosing and treating pediatric conditions

- To clarify or supplement messages received from practitioners or other sources

- To confirm or provide reassurance for existing knowledge or beliefs

- To seek advice or support on parenting issues

Sources for pediatric health information

Participants reported that the most common way of finding pediatric health information on the Internet was through search engines, and when they found websites that they liked they would often return to the same sites. Other common ways in which the participants reported finding websites with health information were through word-of-mouth recommendations and through advertisements and articles in other media, especially parenting magazines.

When asked which websites they visit most frequently for health information, the most popular websites named by the participants fell into the category of *commercial information websites,* and included such examples as BabyCenter.com, ParentsPlace.com, and WebMD.com. Although these websites display commercial advertisements and often sell products, the participants did not see this as a potential conflict of interest. Said one participant: "The purpose of [one commercial information site] I think is to sell you stuff but they answer questions and it seems to me like that information sounds right." Many participants found these sites to be comprehensive and convenient and they liked the fact that they could shop, socialize, and research a wide range of topics all from the same website.

Organizational websites run by not-for-profit entities, and *academic websites*, run by universities and medical centers also

were frequently mentioned as a good place for pediatric health information. Many participants praised these kinds of websites for containing reliable information, but some expressed displeasure that information on these sites, particularly the academic websites, can be too scientific and hard to understand. One mother complained about "...not being able to find what you're looking for and the frustration at ending up in 'journal level detail' when you're wanting 'mom level detail,' but [ideally] you want 'mom level detail' from an expert."

The *commercial product websites* maintained by companies selling specific baby products such as diapers, infant formula, or baby food were the least preferred type of health information website. Many participants reported that they had received direct mail or e-mail from such companies. However, few participants had, or would, go to these sites for health information, primarily because they were perceived to have an "ulterior motive" that undercuts the reliability of the health information they provide. This sentiment was more common among stay-at-home mothers than those mothers who worked outside the home. One mother who was critical of these websites representatively opined, "If [a major baby food manufacturer] sponsors [the website then] they just want to sell this stuff to me."

Determining trust of pediatric health information

Trusting the reliability of information on the Internet was expressed as a serious concern by many focus group participants. When they were asked how they determine which websites to trust for health information, several strategies of determining trust emerged. One strategy involved trying to *determine the motives* of the website owners. If the primary purpose of an organization's website is perceived as the sale of their products, many mothers expressed skepticism for the trustworthiness of the health information presented there. In contrast, if the organization presenting the online information has little or nothing to gain financially by putting out the information, they are more likely to be trusted. In a similar vein, when asked about the relevance of different domain designations (i.e., .edu, .org, .net, .com) to trustworthiness, some participants noted that the Internet domain type can affect their perceptions of trust. As one participant observed, "A university setting I think...has more truth than a dot-com."

Another strategy that participants mentioned for determining the trust of a health website was to try to *identify and evaluate the source of the information* being presented. On many websites, the source of any given page or piece of information may be an individual writer, an organization, or even a different website, but some participants noted that discerning the original source of online information can be difficult. When the source could be determined, the most trusted sources, according to almost all the participants, were physicians and nurses, particularly when the information related to specific illnesses or conditions.

It was also noted that perceived trust in specific web-based sources of pediatric health information could increase over time as readers became more familiar with the source. For example, one participant who frequently visits a commercial information

site, for example, described her perceptions of a pediatrician contributor to the site as follows: "I recognize him and his name because I read a lot of stuff that he writes [and] it is almost like another pediatrician to have available... I get to know him the same as you would [if you] have your own personal relationship." Along the same lines, some participants liked it when the source's name and picture were included. For example: "I think for me, psychologically, I like to see a person's face, see what they look like, just because it helps me to decide if I trust them or not."

In contrast, however, perceptions of source trustworthiness can break down when participants observe disagreements among the experts. For example, one mother noted, "...All of these pediatricians are basically contradicting themselves and they are experts. So if they're experts, why should we listen to them when they are contradicting each other? But that's one thing good about the Internet. You get on and you see all of these different ideas and you realize these guys aren't real experts. It makes you feel better as a mom."

The other highly trusted source for pediatric health information on the web was other parents, but only in specific situations. Other parents were commonly seen as a good source of support, reassurance, and advice on behavioral issues and parenting tips, but their advice was considered more suspect on issues of medical diagnoses and treatment. For example, when considering a webpage on pediatric skin cancer prevention written by a parent, one participant observed, "On this topic, I don't think what other parents have to say is of any use to me. On other things I think it is, but not on this subject."

Finally, the other strategy participants reported using to assess the trustworthiness of health information websites had to do with *information repetition and convergence*. Several participants reported that information appearing many times in many places is often considered to be more trustworthy than information that is not repeated. As one mother noted, "If you can find it in five or six spots [then] in my mind it is more likely that it is probably valid than if you read it one place but no one else is corroborating that or agreeing with it."

Information convergence with other non-Internet reference sources was also related to perceptions of trust. Almost all the participants reported that they would believe pediatric health information to be true if they received consistent information about it on the Internet, from their doctor, and from other parents. One participant described her process of seeking information convergence as follows: "I tend to use books first and talk to people second like [other] mothers... or relatives and then thirdly either go to the Web first to try to find more complimentary information and then check with the pediatrician." Another noted, "It doesn't matter what I read in a book or what I look up on the net, I'm going, in the end, if it is a health issue, [to] go ask my doctor. And if I don't like his answer, I'll ask another doctor." See Table 2 for a list of the strategies participants gave for determining the credibility of pediatric websites.

Table 2. How mothers determined trust of pediatric health information

- Determine the motives of the website providers

- Identify the source of the information being presented

- Look for repetition and convergence of information from multiple sources

Discussion

Understanding why, where, and how parents use the Internet to obtain pediatric health information is particularly important for caregivers and health educators because parents are turning to this information source with increasing frequency. Madden and Raine estimated that 80% of all Internet users, or more than 70 million Americans in December 2002, sought health information online [12]. About half of these online health information seekers are thought to have been seeking health information for themselves and the other half were searching for health information for someone else [13]. Almost 60% of parents with Internet access are active seekers of online health information [3]. These rates are likely to increase as more and more families obtain Internet access from home and more pediatric websites become available online.

The mothers in our study reported going online to learn more about the stages of fetal and child development, especially for their first child. This finding suggests that pre-natal and post-natal women can be high information seekers and that these time periods offer important opportunities for reaching mothers and mothers-to-be with essential pediatric health information. The information that these women found most useful were messages that were matched, or tailored, to their specific stage of pregnancy or the developmental stage of their child. The preferences these mothers expressed for personalized messages are consistent with other studies that have found strong preferences for tailored health messages over generic health messages [14-16]. Recent studies have found that web-based tailored messages are more effective than non-tailored web messages at changing participants' health-related beliefs and behaviors, [17,18] but there have been no known studies on the effectiveness of web-based tailored interventions for pregnant women or new mothers. This potential opportunity for effective prenatal and postpartum interventions warrants additional attention and research.

The primary reasons given by the mothers in our study for going online for health information were to research specific conditions or symptoms that their child was experiencing, and to get advice and support on parenting related issues. These online information seeking behaviors are consistent with studies of other Internet-using populations which have found that Internet users frequently seek online information on specific health conditions [19] and that they seek advice and social support for the different specific situations and challenges they face [20]. Our findings also revealed that the mothers' most trusted sources for these two types of information are different; not surprisingly, pediatricians and pediatric nurses were described as the most trusted source for online pediatric health information and other parents as the most trusted source for advice on parenting and for social support.

Our study participants expressed a great deal of overall skepticism and concern about the trustworthiness of sites, especially those that focus on selling specific baby-related products, which are similar to those found in other studies of Internet users that have revealed that many people do not trust or believe much of the information they receive online [21-22]. One study similar to this one that explored perceptions about online human genetics communication among Internet users found that most users would take the health information they received on the Internet with a "grain of salt." [23]

Previous research with Internet users found multiple strategies for assessing the credibility of health related websites [7]. The most trusted sites included those from official authorities, and with professional layouts, understandable writing, and appropriate source citations [7]. An alternative strategy for assessing credibility that was revealed in our study was the use of repetition, i.e., many participants reported a greater trust of online health information when it was repeated on multiple websites or when the information was discovered to be consistent across multiple communication channels. This finding is consistent with research that has found that online health information seekers often feel reassured by advice they find that is repeated at more than one site and that matches what they already knew [16]. Using this type of "information convergence" strategy to establish accuracy of health information can be a useful way to confirm that ideas or opinions are widely held and accepted, especially when multiple sources of information are considered such as personal pediatricians, books, and peer-reviewed articles. This approach may be somewhat less effective, however, when convergence is sought only for unregulated information that appears on the web.

Due to the World Wide Web's vast size and unregulated nature, websites are likely to exist that advocate almost every conceivable position on any controversial pediatric topic. Therefore, if a parent seeks a supporting opinion for a potentially dangerous or inappropriate course of treatment for their child, they are likely to find multiple websites advocating that position if they look hard enough. To help prevent this from happening, practitioners should be aware that parents often seek "second opinions" online, especially when they don't like or understand what they have been told. Practitioners may consider recommending specific websites to their patients and their families that are known to be accurate, trustworthy, and consistent with best practices. Experts recommend that Internet health seekers allow ample time for conducting a thorough search, visit at least four different sites, determine the sponsor of each online health site, and identify the date when the information was last updated [19].

A number of limitations should be considered when interpreting the data presented in this study. As with most qualitative research, caution should be exercised in generalizing our findings to all mothers or other populations of mothers of young children. In addition, focus group research uses self-reporting techniques, and it is possible that some participants' comments are inconsistent with their actual experiences. Participants in this study had higher than average educational levels and were all from the greater metropolitan area of one medium-sized city in the Southeastern US. In addition, the sample had minimal racial and ethnic diversity, likely a result of the locations from which the participants were recruited. All participants were required to have used the Internet at least one time in the previous 6 months, but they were not required to have specifically looked up pediatric health information during that time period. Although almost all participants acknowledged viewing pediatric information online, it is possible that some participants' comments referred to older or more theoretical experiences. In addition, only mothers were recruited for this study because women are twice as likely as men to seek online health information for their children, [2] and it is possible that fathers have considerably different experiences and perceptions about online health information. Finally, the number of focus groups conducted and the overall number of participants was relatively small. Despite the fact that the data demonstrated considerable convergence, it is entirely possible that other important opinions and perspectives were missed.

In conclusion, the findings from this study suggest that the pre-natal and post-natal periods may represent "teachable moments" when women are high information seekers for online pediatric information. Because there are countless pediatric health-related websites available presenting widely divergent opinions of varying degrees of quality and accuracy, it is important that practitioners be educated about high-quality, accurate pediatric health websites and encourage their patients to avoid inappropriate websites. Participants largely preferred websites with tailored health information, pediatric content that is presented by caregivers, and parenting advice that is presented by other parents. Information that is repeated consistently across multiple sources or websites may increase perceptions of trust. Future research should seek to replicate and expand upon these findings with more diverse populations and through quantitative surveys administered to larger and more generalizabile samples of mothers and fathers.

Acknowledgments

Conflicts of Interest

None declared.

Multimedia Appendix

Focus Group Guide: [PDF File, 21KB - jmir_v6i1e7_app1.pdf]

References

1.   Eng TR. The eHealth Landscape: A Terrain Map of Emerging Information and Communication Technologies in Health and Health Care. Princeton, NJ: The Robert Wood Johnson Foundation; 2001.

2.   Fox S, Rainie L, Horrigan J, Lenhart A, Spooner T, Burke M, et al. The online health care revolution: How the web helps Americans take better care of themselves. Washington, DC: Pew Internet & American Life Project; 2000. URL: http://www.pewinternet.org/reports/toc.asp?Report=26

3.   Allen K. Parents online. Washington, DC: Pew Internet and American Life Project; 2000. URL: http://www.pewinternet.org/reports/toc.asp?Report=75

4.   Pandolfini C, Impicciatore P, Bonati M. Parents on the web: risks for quality management of cough in children. Pediatrics 2000 Jan;105(1):e1 [FREE Full text] [Medline: 20085374] [doi: 10.1542/peds.105.1.e1]

5.   Impicciatore P, Pandolfini C, Casella N, Bonati M. Reliability of health information for the public on the World Wide Web: systematic survey of advice on managing fever in children at home. BMJ 1997 Jun 28;314(7098):1875-1879 [FREE Full text] [Medline: 97367429]

6.   Eysenbach G, Powell J, Kuss O, Sa ER. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. JAMA 2002 May 22;287(20):2691-2700 [FREE Full text] [Medline: 22016241] [doi: 10.1001/jama.287.20.2691]

7.   Eysenbach G, Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. BMJ 2002 Mar 9;324(7337):573-577 [FREE Full text] [PMC: 11884321] [Medline: 21881326] [doi: 10.1136/bmj.324.7337.573]

8.   Morgan DL. Focus Groups as Qualitative Research (Qualitative Research Methods). Thousand Oaks, CA: SAGE Publications; Oct 23, 1996.

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9.   Stewart DW, Shamdasani PN. Focus Groups : Theory and Practice (Applied Social Research Methods). Newbury Park, CA: SAGE Publications; Aug 1, 1990.

10.   McGuire W. Theoretical foundations of campaigns. In: Rice RE, Atkin CK, editors. Public Communication Campaigns. Newbury Park, CA: SAGE Publications; Jun 1, 1989:43-65.

11.   The Ethnograph [computer program]. Version 5.0. Amhurst, MA: Qualis Research Associates; 1999.

12.   Madden M, Rainie L. America's Online Pursuits: The Changing Picture of Who's Online and What They Do. Pew Internet & American Life Project. 2003. URL: http://www.pewinternet.org/reports/pdfs/PIP_Online_Pursuits_Final.PDF [accessed 2004 Feb 19]

13.   Fox S, Rainie L. Vital Decisions: How Internet users decide what information to trust when they or their loved ones are sick. Pew Internet & American Life Project. 2002. URL: http://www.pewinternet.org/reports/pdfs/PIP_Vital_Decisions_May2002.pdf [accessed 2004 Feb 19]

14.   Skinner CS, Strecher VJ, Hospers H. Physicians' recommendations for mammography: do tailored messages make a difference? Am J Public Health 1994 Jan;84(1):43-49. [Medline: 94106682]

15.   Campbell MK, Bernhardt JM, Waldmiller M, Jackson B, Potenziani D, Weathers B, et al. Varying the message source in computer-tailored nutrition education. Patient Educ Couns 1999 Feb;36(2):157-169. [Medline: 22891270] [doi: 10.1016/S0738-3991(98)00132-3]

16.   Bull FC, Kreuter MW, Scharff DP. Effects of tailored, personalized and general health messages on physical activity. Patient Educ Couns 1999 Feb;36(2):181-192. [Medline: 22891272] [doi: 10.1016/S0738-3991(98)00134-7]

17.   Bernhardt JM. Tailoring messages and design in a web-based skin cancer prevention intervention. Int Electronic Journal of Education 2001;4:290-292.

18.   Oenema A, Brug J, Lechner L. Web-based tailored nutrition education: results of a randomized controlled trial. Health Educ Res 2001 Dec;16(6):647-660 [FREE Full text] [Medline: 21639060] [doi: 10.1093/her/16.6.647]

19.   Fox S, Rainie L. Vital Decisions: How Internet users decide what information to trust when they or their loved ones are sick. Pew Internet & American Life Project. 2002. URL: http://www.pewinternet.org/reports/toc.asp?Report=59 [accessed 2004 Feb 19]

20.   White M, Dorman SM. Receiving social support online: implications for health education. Health Educ Res 2001 Dec;16(6):693-707 [FREE Full text] [Medline: 21639063] [doi: 10.1093/her/16.6.693]

21.   Rosenbaum MD, Altman D, Brodie M, Flournoy R, Blendon RJ, Benson J. Survey shows widespread enthusiasm for high technology. Washington, DC: National Public Radio, Henry J. Kaiser Family Foundation, Harvard University Kennedy School of Government; 2000. URL: http://www.npr.org/programs/specials/poll/technology/

22.   Newport F, Saad L. A matter of trust. American journalism review 1998 Aug [FREE Full text]

23.   Bernhardt JM, Lariscy RAW, Parrott RL, Silk KJ, Felter EM. Perceived barriers to Internet-based health communication on human genetics. J Health Commun 2002;7(4):325-340. [Medline: 22243103] [doi: 10.1080/10810730290088166]

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Original Paper

Online Consumer Surveys as a Methodology for Assessing the Quality of the United States Health Care System

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Abstract

Background: Interest in monitoring the quality of health care in the United States has increased in recent years. However, the policy objectives associated with collecting this information are constrained by the limited availability of timely and relevant data at a reasonable cost. Online data-collection technologies hold the promise of gathering data directly and inexpensively from large, representative samples of patients and consumers. These new information technologies also permit efficient, real-time assessment in such areas as health status, access to care, and other aspects of the care experience that impact health outcomes.

Objective: This study investigates the feasibility, validity, and generalizability of consumer online surveys to measure key aspects of health care quality in the United States.

Methods: Surveys about the health and health care experiences of a general adult population and of adults with diabetes were administered online and by telephone. The online survey drew from a sample frame of nearly 1 million consumers and used a single e-mail notification. The random-digit-dial methodology included 6 follow-up calls. Results from the online sample were compared to the telephone sample and to national benchmark data.

Results: Survey responses about quality of care collected using online and telephone methods were commensurate once they were weighted to represent the demographic distribution of the 2000 United States Census. Expected variations in health and health care quality across demographic and socioeconomic groups were largely observed, as were hypothesized associations among quality indicators and other variables. Fewer individuals were required to be contacted to achieve target sample sizes using online versus telephone methods. Neither method yielded representative cohorts of nonwhite individuals.

Conclusions: Conclusions about the level and variations in health care quality in the United States are similar using data collected in this study compared to data collected using other telephone-based survey methods. As is typical for national telephone surveys conducted by the National Center for Health Statistics, stratified sampling and weighting of survey responses is necessary for results to be generalizable. Online methods are more appropriate for understanding health care quality than for conducting epidemiologic assessments of health in the United States.

KEYWORDS

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Introduction

Recent years have seen a marked increase of interest in monitoring the quality of health care in the United States. Congress has mandated the annual release of a National Healthcare Quality Report, which will include results from consumer-reported surveys on health care quality [1]. Congress, a presidential commission, and the National Quality Forum have all called for publication of consumer-centered quality performance information, and the administrator of the Medicare program has indicated the government's intention of releasing performance data for nursing homes, hospitals, and perhaps even physicians [2,3]. State Medicaid and State Children's Health Insurance Programs (SCHIP) are required to assess and report on quality of care provided to consumers enrolled in these programs [4,5].

Need for Timely and Efficient Collection of Quality Information

These policy objectives are constrained by the limited availability of timely and relevant data at a reasonable cost. Often, information strategies for health care quality must rely on datasets defined and populated for other reasons, such as documentation of financial transactions, public health surveillance, or contractual oversight and audit. Seldom do such assessment systems address the health care quality concerns of patients and consumers, and rarely do they capture their experiences or attitudes.

Consequently, a tension exists between the policy objective of evaluating our success at creating a more-responsive health system that achieves priority health goals and our dependence on an information infrastructure unable to capture the necessary data to determine whether these goals are being achieved. Two trends offer some hope of resolving this tension. First, scientists have developed and validated an extensive library of patient survey instruments over the past 20 years. Tools now permit us to measure the performance of the health system along the dimensions of health care outcomes and the provision of clinically-appropriate, patient-centered care [6- 12]. Second, new information technologies hold the promise of gathering data directly and inexpensively from large, representative samples of patients and consumers. Online data-collection technologies also permit efficient, real-time assessment in such areas as health status, access to care, and other aspects of the care experience that affect health outcomes [13- 14]. Given the potential efficiencies and expediency of collecting data online, as well as growing limitations in telephone-based and/or mail-based surveys, it is clearly worthwhile—perhaps vital—that we develop and test online methods for capturing consumer-reported information on quality of health care.

The Challenges of Web-Based Patient Surveys

All modes of consumer-survey administration entail challenges of measurement error, nonresponse error, and, particularly, coverage error. Online methods may be helpful in reducing some of these sources of error, but may also encounter new challenges in other sources of error.

Measurement Error

Web-based surveys introduce a new mode of interaction with respondents. The online experience involves both technical and contextual changes that may cause variations from how the same individuals would answer questions if presented in person, on the telephone, or by mail. Among technical differences are the presentation of questions and responses on computer screens, and variations in browser layouts, colors, text, and communication speeds. Contextual factors include users' ability to review and change prior answers, look ahead to other content, "multi-task," or start and stop during a session. Studies evaluating Web-based survey-mode effects have generally shown them to more closely resemble self-administered mail surveys than interviewer-administered telephone surveys, though with lower item nonresponse [13,15] and the potential for immediate data analysis and feedback to sponsors and respondents [16,17]. To ensure consistent user experiences and reduce measurement error, a consensus set of procedural recommendations analogous to those for mailed and telephone administered surveys is emerging for conducting Web-based surveys [18- 20].

Non-Response Error

Continuing changes in consumer telephone behavior have increased and redefined nonresponse error in phone surveys [21,22]. The common use of answering machines and of technologies for caller identification and unknown-caller blocking all contribute to nonresponse bias for telephone surveys. Consumer resistance to receiving telephone calls by telemarketers is reflected in the Do-Not-Call registry recently required by Congress and implemented by the Federal Trade Commission [23]. While survey researchers conducting surveys for not-for-profit or public-interest purposes are not prevented from calling individuals in this registry, the overarching resistance and resentment expressed by consumers regarding calls made to their home during evenings and weekends could generalize to a resistance to respond to calls to conduct these types of surveys.

Although researchers have begun to study the extent and causes of nonresponse error to e-mail and Web-based surveys, it is not well-documented and remains an especially-serious concern of methodologists when considering the use of the Web to conduct population-based surveys intended for use in policy contexts [21,23,24]. Documented reasons for nonresponse range from traditional questions of content interest to respondents' use of multiple e-mail accounts and defunct or infrequently-accessed e-mail accounts [21,25,26]. The emerging consensus procedures focus on the importance of repeat contacts, tracking nondelivery to e-mail accounts, and incentives to maximize response rates.

Incomplete Coverage

Errors are introduced in national telephone surveys because of households without telephones. Similarly, incomplete Internet access, or coverage, introduces error in national estimates based on online survey data. While the majority of Americans have access to the Web, there remain significant economic, cultural, and educational disparities. As of mid-2000, the US (United States) government estimated that only13% of persons with

annual incomes under $15000 had Internet access in their homes, compared with 78% of those with incomes over $75000 [27]. Overall, whites enjoy greater Web access than do African-Americans and Hispanics [27]. These disparities may be rapidly changing, however. According to a 2001 UCLA report, 72% of all Americans have Internet access, including 65% with less than a high school education [28]. Certain demographics can be specifically targeted through Web technology—for example, customers of America Online, users of eHealth services, or populations sharing an e-mail domain who can be sent a request to complete a survey. Examples could be university-affiliated populations or employees of large companies. Also, larger proportions of low-income and elderly Americans increasingly use the Internet and can be sampled in online surveys [27].

Researchers advocate various ways of responding to the noncoverage and nonresponse challenges inherent in all survey administration modes, including Web-based surveys:

1. adjusting nonrepresentative completed samples according to characteristics known of both the starting sample and underlying populations [29- 30]
2. coupling participant recruitment using random-digit dialing with the efficiencies and interactivity of the Web [31]
3. restricting use of online data collection to studies of fully-covered populations (eg, university surveys and subscribers to specific Web sites)
4. delaying use of Web surveys until coverage improves and methodological developments take place [32].

The Robert Wood Johnson Foundation (RWJF) and the Foundation for Accountability (FACCT) recognized the potential value of conducting Internet-based surveys to calculate national estimates of health care quality. In 2000 and 2001, as part of the Robert Wood Johnson Foundation National Strategic Indicators Project (NSIP), online surveys were fielded to assess health care quality for children, teens, and adults with and without chronic conditions. Survey topics were identified as relevant for each of the 5 Foundation for Accountability Consumer Information Framework (CIF) domains (the basics, staying healthy, getting better, living with illness, and changing needs) and types of measures (health outcomes, appropriate clinical care, and patient-centered experience of care) [33]. The Consumer Information Framework has been adapted for use in the Congressionally-mandated National Health Care Quality Report [1] to structure the identification and communication of quality information to the public.

In this paper, we report the extent to which data derived from a national online sample of the general adult population and from a sample of adults with diabetes meet initial criteria for use in characterizing the performance of health care systems.

Four research questions are preliminary to the overall feasibility and validity of using Web-based surveys to estimate health care quality:

- Are online survey response rates (derived from a sampling frame recruited using opt-in Internet methods) of sufficient size and representation to estimate health care indicators for the US population?

- Do estimates of key health status and health care system quality variables demonstrate face validity, compared to other national studies?
- Do these estimates demonstrate concurrent validity, such that demographic and other correlates of health status and health care system performance match those observed in national telephone-based surveys?
- Are survey scale data collected online psychometrically reliable?

Methods

This study reports both online and telephone-administered health care survey results for adults age 18 and over, as well as for adults with diabetes. Also used are data from adult respondents to the 1999 Behavioral Risk Factor Surveillance Survey (BRFSS) and the 1998 National Health Interview Survey (NHIS) administered by the US Centers for Disease Control and Prevention (CDC).

Data Collection

Online Surveys

A market research firm, Common Knowledge, Inc, recruited a panel of approximately 1 million individuals, using Internet advertisements intended to attract a group with diverse demographic and psychographic characteristics. Approximately 70% of the panel was recruited online, the remaining 30% through traditional direct-mail and telephone contact. Panelists were invited to participate in only one study per month to prevent "professional" survey takers from responding and to minimize respondent fatigue.

Two waves of sampling and data collection took place for the general-adult and adult-diabetes online surveys. In the first wave, separate stratified random samples were drawn, each representing the US population along the dimensions of age, sex, and education using 4 age groups (18-24, 25-44, 45-64, over 65) and 4 educational groups (less than high school, high school/GED [General Equivalency Diploma], some college, college or more). A standard self-reported screening tool was used to identify individuals age 18 and over and those with diabetes. For the general adult survey, 13400 invitations were sent in the first wave of data collection. Diabetes-qualified respondents were screened as part of a larger effort to identify several chronic illnesses. Once a person qualified for one condition they were routed to complete the survey for persons with that condition until target sample sizes for each condition were achieved. As such, no sample-wide qualification rate for adult diabetes is available. A second wave of 1400 invitations oversampled individuals with Spanish surnames or who lived in zip-code areas with disproportionate numbers of African-Americans and/or Hispanics. An online survey research firm, E-valuations, Inc, sent invitations and collected data for both waves, using the sampling design and surveys developed by the Foundation for Accountability and the Robert Wood Johnson Foundation. Each respondent was given a unique 5-digit access code to ensure that the survey was taken only once. Those who completed it were entered into a drawing for a $250 cash

prize. No reminder e-mails were sent, nor were nonworking or dormant e-mail addresses tracked.

Telephone Surveys

Adults age 18 and over constituted the sampling frame for the 2 telephone surveys. Wirthlin Associates, Inc identified individuals by means of traditional random telephone-survey methods, and used the sampling design and surveys developed by the Foundation for Accountability and the Robert Wood Johnson Foundation to conduct the surveys. Candidate telephone numbers were randomly selected and call attempts made until the target completed sample sizes of 400 for each survey was reached.

Measures

This study evaluates the Internet methodology for both the general-adult and adult-diabetes samples, using demographic variables and the following topics. Sources of survey items for each topic are provided in the reference associated with each of these topics:

1. days lost because of poor physical health problems [34]
2. self-assessed overall health status [35]
3. health insurance status/affordability of care (Robert Wood Johnson Foundation, oral communication, in person and by telephone, 2000)
4. presence of a regular personal doctor [34]
5. utilization of health care services [36]
6. smoking behavior [34]
7. doctors advising smokers to quit [36]
8. drinking behavior [34]
9. routine retinal eye exams (diabetes sample only) [34].

We selected these variables based on the availability of external benchmarks and representation of a range of health and health care quality topics.

The psychometric reliability of the following survey scales constructed using several survey items was also assessed (these are the multi-item survey scales referred to below in the "Data Analysis" part of "Methods"). A reference for each multi-item survey scale is provided in the reference associated with each of these scales:

1. getting medical care quickly [37]
2. getting dental care quickly [37]
3. shared decision making (diabetes only) [38]
4. self-care education and support (diabetes only) [39].

Data Analysis

We calculated response rates for the online general adult survey as the ratio of the completed sample size to the number of e-mail invitations needed to achieve this sample. The response rate for the online adult-diabetes survey was the proportion of the people completing the survey who were positively identified as having diabetes. Neither rate accounts for nonworking or dormant e-mail addresses. Telephone response rates were the ratio of completed sample size to the number of randomly-selected, working residential phone numbers that had to be called to achieve this sample size.

Survey responses for adults with diabetes were weighted using diabetes-specific age and sex distributions from the 1999 Behavioral Risk Factor Surveillance Survey [34]. General adult survey responses were weighted for age, sex, educational level, and presence of a chronic condition using distributions from the 2000 National Health Interview Survey (Robert Wood Johnson Foundation, oral communication, in person and by telephone, 2000). These distributions were used in lieu of those available from the US Bureau of the Census through the Current Population Survey (CPS) because chronic-condition status was not available from the Current Population Survey [40].

We compared weighted results from the online and telephone surveys for variables listed above to available benchmarks using either the 1999 Behavioral Risk Factor Surveillance Survey or the 1998 National Health Interview Survey. For online, telephone, and benchmarking dataset samples, we used regression analysis methods to evaluate patterns of variation across population subgroups for selected health and health care quality variables. Dependent variables for the general adult sample included health insurance status, having a regular doctor or nurse, physician counseling to quit smoking (for smokers), and poor health days in the last month. Dependent variables for the adult-diabetes sample included receipt of a routine retinal exam, use of health care services, smoking behavior, and poor health days in the last month. Independent variables were age, sex, race, education, and income, plus health insurance status and having a regular doctor or nurse, except where *health insurance* or *regular doctor or nurse* was used as a dependent variable. We compared results across samples in terms of the overall explanatory value of independent variables using the Cox and Snell generalized coefficient of determination [41]. The direction, general magnitude, and significance of the effect of each explanatory variable were also compared across samples for each dependent variable.

Each of the 4 multi-item survey scales (see *Measures,* in *Methods,* above) were evaluated for psychometric reliability using standardized estimates of Cronbach alpha [41]. SPSS version 9.0 was used to conduct data analysis [42].

Results

Response Rates, Response Bias, and Representativeness

Of the approximately 13400 e-mail invitations sent for the online general adult population survey, 2324 individuals responded and completed at least 80% of the survey, resulting in a 17.3% raw response rate. Based on industry norms, we estimate that at least 10% to 15% of e-mail addresses are nonworking or dormant. Assuming this, the true response rate for the online general adult survey is 19% to 20%. For the general adult population telephone survey, approximately 4300 working, residential phone numbers had to be dialed to achieve the target sample size of 400. This resulted in an estimated 9.3% response rate after adjusting for nonworking and nonresidential phone numbers. Completed survey samples for the online and telephone adult-diabetes surveys were 1048 and 397 respectively.

Table 1. Demographic indicators for Robert Wood Johnson Foundation indicator survey: general adult population

	2001 Online Unweighted (N = 2324), %		2001 Telephone Weighted * (N = 2315), %	Unweighted (N = 400), %	Weighted † (N = 396), %	United States Current Population Survey, %
	Sampled ‡	Actual				
Gender §						
Male	48.3	50.9	48.0	48.0	48.0	48.0
Female	51.7	49.1	52.0	52.0	52.0	52.0
Age §						
18-24	12.0	7.8	12.9	3.8	12.9	13.2
25-44	42.6	37.0	42.1	39.4	42.1	40.9
45-64	30.4	40.1	28.8	37.4	28.8	29.7
65 or older	15.0	15.1	16.2	19.4	16.2	16.2
Education§						
Less than high school	15.6	11.9	15.1	7.0	11.0	16.9
High school/GED (General Equivalency Diploma)	33.5	24.4	33.7	23.6	37.8	32.8
Some college	24.2	37.3	30.2	34.3	24.2	27.1
College or more	26.7	26.4	21.0	35.1	27.0	23.2
Income§						
Less than $15000		12.6	13.3	8.0	9.4	10.5
$15000-$24999		17.4	18.4	14.6	18.3	12.0
$25000-$34999		17.1	17.2	17.5	22.4	11.9
$35000-$49999		19.1	19.5	17.5	14.5	16.5
$50000-$74999		19.0	18.8	22.9	20.4	21.2
$75000 or more		14.8	12.8	19.5	15.0	27.9
Race/Ethnicity §						
White		89.6	80.0	80.0	76.0	73.3
African-American		2.3	7.1	6.3	6.9	11.6
Asian		1.4	1.4	2.3	2.2	3.9
Hispanic		3.0	8.0	6.6	9.9	10.5
Other		3.7	3.5	4.8	5.0	0.7

* Weight based on 1998 NHIS (National Health Interview Survey) distribution of age, sex, education, and presence of chronic condition.

† Weight based on 1998 NHIS distribution age, sex, and education.

‡ Distribution of original population from which the population was sampled.

§ Some differences between the United States Current Population Survey and both the online and telephone responding populations in this study were at the .05 level of significance.

Table 1 and Table 2 summarize the demographic characteristics of the unweighted and weighted online and telephone survey samples. Overall, respondents to the online general adult survey match the distribution of the sampled population, with some underrepresentation of individuals age 18 to 24 and overrepresentation of individuals age 45 to 64 and individuals reporting more than a high school education. Both the unweighted online and telephone general-adult completed survey samples underrepresent nonwhite individuals, those with less than a high school education, and those with incomes over $75000. Compared to the Current Population Survey, both general adult samples overrepresent individuals with a college education (or more) and incomes of $15000 to $35000. The telephone general-adult sample was more likely to underrepresent those with less than a high school education and overrepresent those with a college education. Similar results were found in both adult-diabetes samples (Table 2). However, while the telephone diabetes survey sample dramatically underrepresented individuals under age 44, and overrepresented those over age 65 and with incomes over $75000, this was not

the case for the online adult-diabetes survey sample. Neither the online nor telephone methods resulted in samples properly representing racial groups with diabetes.

Table 2. Demographic indicators for Robert Wood Johnson Foundation indicator survey: adult-diabetes population

	2001 Online		2001 Telephone		Behavioral Risk Factor Surveillance Survey	
	Unweighted (N = 1048), %	Weighted * (N = 1035), %	Unweighted (N = 396) %	Weighted * (N = 387), %	Diabetes only † (N = 12214135), %	
Gender ‡						
Male	45.0	46.4	38.1	46.2	1.84	
Female	55.0	53.6	61.9	53.8	9.15	
Age‡						
18-24	1.1	1.2	0.3	0.8	6.1	
25-44	19.0	16.3	2.3	14.1	8.31	
45-64	52.5	43.5	46.5	43.6	0.34	
65 or older	27.4	39.0	50.9	41.5	6.14	
Education‡						
Less than high school	7.5	7.2	12.4	11.3	3.62	
High school/GED (General Equivalency Diploma)	25.3	25.4	33.3	32.1	8.23	
Some college	41.8	41.9	28.8	29.5	8.12	
College or more	25.4	25.5	25.5	27.1	1.91	
Income‡						
Less than $15000	13.9	13.9	20.9	20.7	5.42	
$15000-$24,999	17.1	17.7	19.7	18.1	5.32	
$25000-$34,999	19.2	19.2	15.1	12.8	1.71	
$35000-$49,999	23.4	24.4	16.2	16.2	9.41	
$50000-$74,999	17.9	16.9	14.2	16.8	6.11	
$75000 or more	8.5	7.9	13.9	15.4	4.8	
Race/Ethnicity‡						
White	90.6	91.2	83.0	83.5	4.66	
African-American	3.1	2.8	9.4	9.7	4.41	
Asian	0.9	1.0	0.3	0.2	9.1	
Hispanic	2.7	2.4	3.2	2.9	9.41	
Other	2.7	2.6	4.1	3.7	4.2	

* Weight based on 1998 NHIS (National Health Interview Survey) distribution of age and sex of Type II diabetes population. Although the online and telephone data are both weighted to the same NHIS data, slight differences in the distributions occur because the cell for males 18-24 was 0 for the telephone sample, making it impossible to create a weight for that group.

† Weighted to US population; unweighted N = 9496.

‡ Some differences between characteristics of the population of people with diabetes using the BRFSS and both the online and telephone responding populations in this study were observed at the .05 level of significance

Comparison to Other National Studies

Table 3 and Table 4 compare results from both the general-adult and adult-diabetes online surveys to those obtained from the telephone surveys and benchmark data reported in other national studies. For the general adult population, the weighted online-survey results are not significantly different from those derived from the Behavioral Risk Factor Surveillance Survey and the National Health Interview Survey on 7 of the 12 health statuses, access to care, utilization of care, and clinically-appropriate health and health care quality indicators, including: (1) presence of health insurance, (2) having a regular doctor or nurse, and (3) receipt of advice to quit smoking for smokers. For the sample of persons with diabetes, results from

the online survey were not significantly different from the BRFSS or NHIS benchmarks on 7 of the 13 indictors used, including (1) self assessed health status, (2) presence of health insurance, (3) having a routine checkup, (4) getting a retinal eye exam at least once in the least year, (5) receipt of advice to quit smoking for smokers, and (6) routine retinal exams for diabetics.

In the general-adult population survey, we observed higher proportions of individuals reporting 7 or more poor health days, fair or poor health status, and smoking.

In addition to comparing point estimates produced by this online survey to those produced by national benchmark datasets, we also evaluated how these datasets compare in terms of identifying variations and disparities in the health and health care quality across demographic subgroups as well as according to characteristics such as health insurance status and presence of a regular doctor. Table 5 and Table 6 present results from logistic regression analyses conducted to evaluate patterns of variation observed using data collected online versus data collected by telephone and versus telephone-based national benchmark datasets (BRFSS and NHIS).

The independent variables included in this analysis had similar explanatory power for dependent variables from the general adult survey whether data were collected using online or telephone methods. Specifically, at the low end, the demographic and health care related independent variables explained 5% to 13% of the variation observed in reports of days lost because of poor health for the national dataset sample (5%), the telephone sample (13%), and the general adult online sample (9%), respectively. At the high end, these variables explained 25% to 34% of variation observed in the presence of health insurance across all datasets. For the adult-diabetes samples, on the low end, the independent variables used here accounted for less than 5% of the variation observed in rates of high utilization of health care. On the high end, these variables accounted for 11% to 17% of variation observed in rates of smoking for all 3 adult-diabetes samples compared.

Along with the overall explanatory value of independent variables, we observed consistency across the general adult population datasets in terms of the approximate magnitude and significance of effect of specific independent variables. Having a regular doctor and income showed the most consistent and statistically significant effects ($P < .05$). Age and educational level, meanwhile, were the most consistently significant for the dependent variables evaluated for the adult-diabetes samples. No instances were found in which a variable was significant in one sample and also significant in the opposite direction in another. We did find cases of a variable being significant in one sample, but not in another. In most cases, this is attributed to chance or smaller sample size.

Table 3. Comparing online scores to external benchmarks and telephone data on selected health care indicators: general adult population (adjusted to the benchmark by gender and age)

Health Care Indicators—Proportion Who:	Overall			Female			Male		
	Online (N = 2315)	Tele-phone (N = 396)	Bench-mark *	On-line	Tele-phone	Bench-mark	On-line	Tele-phone	Bench-mark
Report ≥ 7 poor health days in last 30 days	22.9	18.3‡	14.0§	26.9	20.0	15.9	18.7	16.5	11.9
Report Excellent or Very good health	45.2	56.6‡	56.1§	38.4	51.4	55.0	52.5	62.2	57.3
Have health insurance	86.3	92.7‡	85.9	87.7	94.7	86.8	84.9	90.6	85.0
Have a regular doctor or nurse:	80.9	84.5	83.3	85.2	88.9	85.3	76.2	79.7	81.3
Had routine check up (last 12 months)	63.9	68.9	70.6§	70.8	76.3	77.7	56.5	60.9	62.9
Had 1-3 doctor visits (last 12 months)†	43.3	49.7‡	44.4	43.9	48.9	43.6	42.7	50.6	45.2
Had ≥ 10 doctor visits (last 12 months)†	15.0	13.9‡	14.2	18.8	17.1	17.8	10.8	10.5	10.3
Delayed care due to cost	21.5	10.8‡	10.3§	26.0	12.5	11.8	16.7	9.0	8.6
Currently smoke	35.0	25.1‡	22.5§	34.3	21.5	20.3	35.8	29.0	24.8
Smoke and were advised to quit by doctor	52.2	50.0	55.9	57.8	56.7	61.9	46.2	42.8	50.6
Binge drink more than once per month (ie, 5 or more drinks at 1 sitting)	8.2	8.1	9.3	3.7	2.4	3.9	13.0	14.2	14.6
Average number of drinks of alcohol on typical day (drinkers only)	2.5	2.6	2.4	2.1	2.1	2.0	2.8	3.1	2.8

* Weighted N for BRFSS (Behavioral Risk Factor Surveillance Survey) sample is 200000000; unweighted N for BRFSS sample is 159989.

† Based on 1998 NHIS (National Health Interview Survey) data.

‡ Significant difference between Online and Telephone samples: < .05.

§ Significant difference between Online and BRFSS samples: < .05.

Table 4. Comparing online scores to external benchmarks and telephone data on selected health care indicators: adult-diabetes population (adjusted to the benchmark by gender and age)

Health Care Indicators—Proportion Who:	Overall			Female			Male		
	Online (N = 1035)	Tele-phone (N = 387)	Bench-mark *	On-line	Tele-phone	Bench-mark	On-line	Tele-phone	Bench-mark
Report ≥ 7 poor health days in last 30 days	35.7	29.7‡	33.6§	37.2	32.4	38.7	32.9	26.7	28.3
Report Excellent or Very good health	18.0	25.9‡	19.1	14.5	25.6	17.3	20.3	26.4	20.8
Have health insurance	93.2	94.0‡	89.1	93.3	95.3	87.9	88.7	92.8	90.5
Have a regular doctor or nurse	96.9	95.3	91.0§	97.0	98.2	93.0	91.8	92.2	89.0
Had routine check up (last 12 months)	91.7	92.0	88.9	91.5	92.9	89.8	91.9	91.1	88.0
Had 1-3 doctor visits (last 12 months)†	24.4	24.8	22.7	22.7	27.8	20.9	23.4	21.7	24.7
Had ≥ 10 doctor visits (last 12 months)†	27.4	28.6	35.7§	31.2	29.7	38.2	22.8	27.4	32.8
Delayed care due to cost	17.6	14.0‡	12.4§	20.4	16.0	13.6	12.4	12.0	11.0
Had retinal eye exam at least once in last year	67.3	68.6	68.9	67.0	70.6	70.3	64.5	68.9	67.6
Currently smoke	19.8	16.9‡	14.6§	21.4	15.9	14.3	17.1	18.2	14.9
Smoke and were advised to quit by doctor	69.9	63.5	66.8	69.5	62.8	66.2	66.8	64.3	67.7
Binge drink more than once per month (ie, 5 or more drinks at 1 sitting)	3.3	2.0	4.2§	1.5	0	1.7	4.6	4.2	6.7
Average number of drinks of alcohol on typical day (drinkers only)	1.8	1.7	2.1	1.5	1.5	1.7	2.1	1.9	2.3

* Weighted N for BRFSS (Behavioral Risk Factor Surveillance Survey) diabetes sample is 12214135; unweighted N for BRFSS diabetes sample is 9496.

† Based on 1998 NHIS (National Health Interview Survey) data.

‡ Significant difference between Online and Telephone samples: P < .05.

§ Significant difference between Online and BRFSS samples: P < .05.

Table 5. Logistic regression results for the general adult population—comparison of odds ratios estimated using online data versus 1999 BRFSS (Behavioral Risk Factor Surveillance Survey) data and telephone supplemental data (cell values are odds ratios calculated using logistic regression analysis methods [43])

	Has Health Insurance			Has Regular Doctor			Advised to Quit Smoking (Smokers Only)			7 or More Poor Health Days in Last Month		
	Online	Telephone	BRFSS	Online	Telephone	BRFSS	Online	Telephone	BRFSS	Online	Telephone	BRFSS
Unweighted N	1992	344	4127*	1992	344	4127*	706	81	682*	1991	344	4069*
R^2	.34	.24	.24	.30	.26	.10	.16	.19	.10	.09	.13	.05
Predictors												
Male	1.03	1.03	.97	.61‡	.53		.57‡	.82	.70	.62§	.81||	.84 49 .
White	1.10	1.21	1.37§	1.38	1.97		.93	1.22	.19||	1.29	.91	1.13 31 .1
Income < $25000	.37‡	.55	.19‡	.79	.42||		.88	1.15	.90	.87	2.45‡	4.19‡ 12.2
Education†	1.85‡	1.77	1.99‡	.79	.92		.83	.95	1.16	1.10	.68‡	.62 6.
Regular doctor	12.60‡	10.30‡	4.28‡	--	--	--	5.27‡	3.16		2.31‡	2.34‡	1.90 9.1
Uninsured	--	--	--	.08‡	.10‡		.24‡	.77	.31	.46‡	1.02	1.25 18 .
Age 18-44	.10‡	.36	.12‡	.18‡	.15||		.44‡	.63	.35	1.22	1.05	1.15 78 .
Age 45-64	.11‡	.28	.15‡	.41||	.33		.83	.73	.46	1.15	1.60§	1.19 32 .1

* BRFSS sample size is small because the question regarding having a regular doctor is asked only of a subset of subjects.

† Education was grouped into high school or less, versus some college or more.

‡ $P < .001$.

§ $P < .01$.

\|\| $P < .05$.

Table 6. Logistic regression results for the adult diabetes population—comparison of odds ratios estimated using online data versus 2 external benchmarks, the 1999 BRFSS (Behavioral Risk Factor Surveillance Survey) or 1998 NHIS (National Health Interview Survey) data and telephone supplemental data (cell values are odds ratios calculated using logistic regression analysis methods [43])

		Had Retinal Eye Exam			Had 10 or More Doctor Visits			Current Smoker			7 or More Poor Health Days in Last Month		
		Online	Tele-phone	BRFSS	Online	Tele-phone	NHIS	Online	Tele-phone	BRFSS	On-line	Tele-phone	BRF-SS
Unweighted N		904	340	256*	903	339	529	904	340	259*	904	337	251*
R^2		.10	.05	.14	.04	.01	.04	.11	.11	.17	.06	.05	.05
Predictors:													
	Male	1.03	.94	.50‡	.75	1.01	.78	.81	.63	.71	.86	.85	
	White	1.44	1.26	.70	1.01	1.06	1.74‡	1.20	1.77	.98	1.00	1.31	
	Income < $25000	.95	1.19	.94	1.81§	1.46	1.55	1.41‡	.97	2.36‡	2.00§	1.78‡	
	Educa-tion†	1.22	1.52	1.52	1.01	1.11	1.61‡	.76	.57	.41	.79	.98	
	Regular doctor	2.11	1.14	2.18	3.13‡	1.06	1.23	1.01	1.06	1.54	.86	.15	
	Unin-sured	.45‖	.31	.20§	.86	1.32	1.18	1.45	.65	.53	.72	.21	
	Age 18-44	.31§	.19‡	.57	1.02	.95	.92	5.77§	5.96‡	4.60‡	1.25	1.24	
	Age 45-64	.46§	.94	1.15	1.13	1.05	1.22	3.97§	3.85§	7.88§	1.82§	1.34	

* BRFSS sample size is small because the question regarding having a regular doctor is asked only of a subset of subjects.

† Education was grouped into high school or less, versus some college or more.

‡ P < .05.

‖ P < .01.

§ P < .001.

Scale Reliability

Cronbach alpha internal consistency scores were .72 or above for each of the 4 multi-item scales observed here (.72-.95), demonstrating their psychometric reliability when online administration is used (Table 7).

Table 7. Cronbach alpha reliability scores for multi-item scales using online data

Scale		Cronbach Alpha
Getting medical care quickly (CAHPS*)		
	General adult 2001	.81
	Adult diabetes 2001	.72
Getting dental care quickly (CAHPS*)		
	General adult 2001	.85
	Adult diabetes 2001	.82
Shared decision making (Diabetes PORT/ FACCT† ONE)		
	Adult diabetes 2001	.95
Self-care education and support (FACCT ONE)		
	Adult diabetes 2001	.93

* CAHPS = Consumer Assessment of Health Plans

† FACCT = Foundation for Accountability

Discussion

This study found evidence that online health care surveys originally designed for mail or telephone administration maintained both psychometric reliability and concurrent validity in results across demographic and other subgroups. More specifically, estimates of access to care, utilization of care, application of clinically appropriate care, and consumer experiences of care were similar to those derived from more traditional methods of obtaining representative samples of the US population.

We were able to achieve a sample representative of the US population in terms of age, sex, and education using a readily-available, opt-in sampling frame that employs relatively low-cost recruitment methods. Basic statistical weighting methods further aligned the responding population sample on these variables. Prior information on the affiliation of individuals included in the Web panel prevented stratified sampling based on race or income. Consequently, we cannot determine whether differences between our completed survey sample and the US population in the proportion of persons representing each racial and income group are due to response biases or inadequate representation in the original sampling frame for this study. Since a great deal of concern focuses on health care for lower-income individuals, it is important keep in mind that this group was, in fact, overrepresented when compared to the US population.

Given the importance of equitably representing the range of racial and economic groups, Web-based panels used for public information about health care quality should strive to include these variables so that stratified sampling may occur and/or assessments of response bias can take place. Here, oversampling methods often used in other national studies were successful in attenuating potential biases in results caused by lower rates of representation among nonwhite racial groups.

Response rates for Internet-based, telephone, or mailed surveys must be calculated in comparable ways and take into account differences in follow-up steps with nonrespondents. In this study, while analogous administration steps were used for both the online and telephone surveys, more-robust follow-up strategy was used for the telephone survey (6 follow-up calls for telephone and no follow-up steps for online survey). In spite of this, the online response rate was higher than for telephone when comparable calculations were used. This finding is true even when nonworking and nonresidential numbers are removed from the telephone sample and similarly nonworking or dormant e-mail addresses are not removed from the online sample. Given the unique sampling and administration processes employed for both surveys, these findings may not be observed in cases where relatively-simple online methods are compared to more-complex and more-costly sampling and administration methods typical of national studies such as the National Health Interview Survey and the National Medical Expenditures Panel Survey. An important question to examine further is whether such extensive follow-up methods are required to generate public information about health care quality and whether

Internet-based methods outlined here may be suitable, especially as Web access continues to expand for all population groups.

Overall, findings from this study demonstrate that many of the sampling and survey administration challenges inherent in telephone and mail modes of data collection are also present for Internet-based methods. In turn, the survey administration, statistical sampling, and weighting approaches used to ensure that data collected via telephone or through mailed surveys yield adequate and representative samples, are also required for data collected via the Internet.

Internet-based data collection is appealing in its potential for allowing information to be collected in a timely and efficient manner. These efficiencies are eroded, however, if costly strategies are required to recruit panels from which sampling may occur and/or when the survey administration process includes extensive nonresponder follow-up and tracking steps. The methods used in this study were selected to be low burden in terms of the sampling frame and administration. This was done in order to begin to explore whether the benefit of obtaining data in a timely and potentially-interactive manner using the Internet can be achieved without incurring costs that diminish the value of doing so when compared to traditional telephone methods used by most nationally-recognized studies.

As these and other issues regarding the use of the Internet to conduct health and health care quality surveys are evaluated, it is worth recalling that our comfort with telephone surveys dates only from the late 1970s, when relatively-sophisticated methodologies were established involving random-digit dialing and multiple contact strategies [24]. In fact, the rise of the telephone survey in the late 1960s and early 1970s was attended by similar methodological concerns as those now associated with Web surveys - and took a decade of research and refinement to resolve. In recent years, the growing use of unlisted numbers, cell phones, call waiting, caller identification, and answering machines have induced a steady decline in response rates and growing disparities in the populations willing to be contacted by telephone. For example, Gallagher et al found that only an elaborate and expensive combination of mail, phone, and door-to-door solicitations produced a respondent pool fully representative of the low-income community [44]. As a result, Dillman has argued that only self-administered surveys - whether made available by mail, interactive voice response, or the Internet - are likely to be successful in the coming years [19].

Results of these analyses suggest that weighted online sampling offers an imperfect but promising avenue for collecting large-scale representative survey data. Overall, conclusions about the level and variations in health care quality in the United States are similar whether based on data collected online or data collected using more elaborate and costly survey methods.

All forms of survey-based data collection involve certain sampling and mode effect biases. Tradeoffs in the biases entailed in online versus telephone based surveys need to be carefully considered by policymakers. As Internet access increases along with the propensity for individuals to resist telephone solicitations, online survey methods may increasingly represent

an efficient, real-time alternative for assessing health and health   care quality in the United States.

Conflicts of Interest

None declared.

References

1. ; Agency for Healthcare Research and Quality, Rockville, MD. AHRQ leading effort to develop national report on health care quality [press release]. 2000 Nov 3. URL: http://www.ahrq.gov/news/press/pr2000/natreppr.htm [accessed 2002 Jul 26]
2. ; Nursing Home Quality Initiative. Centers for Medicare and Medicaid Services. 2002. URL: http://www.cms.gov/providers/nursinghomes/nhi/ [accessed 2002 Jul 26]
3. Hurtado MP, Swift EL, Corrigan JM; Committee on the National Quality Report on Health Care Delivery, Board of Health Care Services. Envisioning the National Healthcare Quality Report. Washington, DC: National Academy Press; 2001. URL: http://www.nap.edu/catalog/10073.html
4. ; Centers for Medicare and Medicaid Services. Medicaid program, Medicaid managed care; final rules. Federal Register 2002 Jun 14;67(115):40988-41116.
5. ; Centers for Medicare & Medicaid Services. State Children's Health Insurance Program (SCHIP). URL: http://www.cms.hhs.gov/schip [accessed 2002 Jul 26]
6. Safran DG, Kosinski M, Tarlov AR, Rogers WH, Taira DH, Lieberman N, et al. The Primary Care Assessment Survey: tests of data quality and measurement performance. Med Care 1998 May;36(5):728-739. [Medline: 98255502] [doi: 10.1097/00005650-199805000-00012]
7. Cleary PD, Edgman-levitan S. Health care quality. Incorporating consumer perspectives. JAMA 1997 Nov 19;278(19):1608-1612. [Medline: 98036275] [doi: 10.1001/jama.278.19.1608]
8. Fowler FJ, Cleary PD, Magaziner J, Patrick DL, Benjamin KL. Methodological issues in measuring patient-reported outcomes: the agenda of the Work Group on Outcomes Assessment. Med Care 1994 Jul;32(7 Suppl):JS65-JS76. [Medline: 94301056]
9. Wasson J, Keller A, Rubenstein L, Hays R, Nelson E, Johnson D. Benefits and obstacles of health status assessment in ambulatory settings. The clinician's point of view. The Dartmouth Primary Care COOP Project. Med Care 1992 May;30(5 Suppl):MS42-MS49. [Medline: 92261086]
10. Ware JE. Measuring patients' views: the optimum outcome measure. BMJ 1993 May 29;306(6890):1429-1430. [Medline: 93299224]
11. Epstein AM. Rolling down the runway: the challenges ahead for quality report cards. JAMA 1998 Jun 3;279(21):1691-1696. [Medline: 98285496] [doi: 10.1001/jama.279.21.1691]
12. Bethell C, Read D, Hochheimer J. CAHPS 2.0H Child survey with children with special health care needs module inserted: HEDIS work-up. Presented to the National Committee on Quality Assurance, Washington, DC, by the Child and Adolescent Health Measurement Initiative, CAHMI 2000.
13. Kwak N, Radler BT. Using the Web for public opinion research: a comparative analysis between data collected via mail and the Web. Presented at: Annual conference of American Association of Public Opinion Research; 2000; Portland, OR.
14. Yun GW, Trumbo CW. Comparative response to a survey executed by post, e-mail, and Web form. J Computer-Mediated Comm 2000;6 [FREE Full text]
15. ; Burke Inc. Internet vs. telephone data collection: does method matter?. 2000. URL: http://www.burke.com/whitepapers/PDF/B.WhitePaperVol2-2000-Iss5.pdf [accessed 2002 Jul 26]
16. ; Foundation for Accountability. Compare your care: a Web-based strategy for consumer activation. Quality counts; final report to Robert Wood Johnson Foundation. Portland, OR: Foundation for Accountability; 2001.
17. ; National Initiative for Children's Healthcare Quality (NICHQ). Home page. URL: http://www.nichq.org/ [accessed 2002 Jul 26]
18. Fischbacher C, Chappel D, Edwards R, Summerton N. Health surveys via the Internet: quick and dirty or rapid and robust? J R Soc Med 2000 Jul;93(7):356-359. [Medline: 20383157]
19. Dillman DA. Mail and other self-administered surveys in the 21st century: the beginning of a new era. 1998 Mar. URL: http://survey.sesrc.wsu.edu/dillman/papers/svys21st.pdf [accessed 2003 Oct 15]
20. Dillman DA. Mail and Internet Surveys: The Tailored Design Method. New York: Wiley; Nov 19, 1999.

21. Atrostic BK, Bates N, Burt G, Silberstein A, Franklin , Winters F. Nonresponse in federal household surveys: new measures and new insights. Presented at: International Conference on Survey Nonresponse; 1999 Oct; Portland, OR URL: http://www.fcsm.gov/committees/ihsng/portland_3__120299.pdf

22. Dillman DA, Carley-Baxter LR. Structural determinants of mail survey response rates over a 12-year period, 1988-1999. In: Proceedings of the Survey Research Methods Section. Alexandria, VA: American Statistical Association; 2000. URL: http://www.amstat.org/sections/srms/Proceedings/papers/2000_063.pdf

23. ; Federal Trade Commission. National Do-Not-Call Registry. URL: https://www.donotcall.gov/ [accessed 2003 Oct 29]

24. Dillman DA, Phelps G, Tortora R, Swift K, Kohrell J, Berck J. Response rate and measurement differences in mixed mode surveys using mail, telephone, interactive voice response and the Internet [draft]. URL: http://survey.sesrc.wsu.edu/dillman/papers/Mixed%20Mode%20ppr%20_with%20Gallup_%20POQ.pdf%20 [accessed 2003 Oct 29]

25. Wiebe EF, Eyerman J, Loft J. Evaluating nonresponse in a Web-enabled survey on health and aging. Presented at: Annual conference of American Association for Public Opinion Research; 2001; Montreal, Canada.

26. Bauman S, Jobity N, Airey J, Atak H. Invites, intros, and incentives: lessons from a Web survey. Presented at: Annual conference of American Association for Public Opinion Research; 2000; Portland, OR.

27. ; National Telecommunications and Information Administration. Falling through the net: toward digital inclusion. 2000 Oct. URL: http://search.ntia.doc.gov/pdf/fttn00.pdf

28. Lebo H. Surveying the digital future. The UCLA Internet report 2001: surveying the digital future. Los Angeles, CA: UCLA Center for Communication Policy; Nov 2001. URL: http://www.ccp.ucla.edu/pdf/UCLA-Internet-Report-2001.pdf

29. Terhanian G, Bremer J, Smith R, Thomas R. Correcting data from online surveys for the effects of nonrandom selection and nonrandom assignment. In: Harris Interactive White Paper 2000.

30. CyBulski KA, Sinclair M, Potter F, et al. Adjusting for nonresponse among Medicaid households that could not be located or were located but did not participate in the Minnesota Managed Care Survey. Presented at: American Statistical Association 161st Annual Meeting; 2001; Atlanta, GA.

31. McCready WC. A national random sample comparison between CATI and Web TV. Presented at: Annual Conference of American Association of Public Opinion Research; 2000; Portland, OR.

32. Crabtree S. Charting new ground: current approaches to the problems of Web-based polling. Gallup Management Journal. 2000 Jul 31. URL: http://web.archive.org/web/20000818091337/http://www.gallup.com/poll/managing/mr000731.asp [accessed 2004 Jan 15]

33. Bethell CD, Lansky D, Read D. Reporting quality information to consumers, FACCT — The Foundation for Accountability. In: Report to the Health Care Financing Administration 1997.

34. ; Centers for Disease Control and Prevention (CDC), US Dept of Health and Human Services. Behavioral risk factor surveillance system survey data. Atlanta, GA: National Center for Chronic Disease Prevention and Health Promotion, Behavioral Surveillance Branch; 1999.

35. Ware JE, Kosinski M, Keller SD. SF-36 Physical & Mental Health Summary Scales: A User's Manual. Boston, MA: The Health Institute, New England Medical Center; 1994.

36. ; National Center for Health Statistics. Questionnaires from the National Health Interview Survey. Hyattsville, MD: National Center for Health Statistics; 1998.

37. ; Agency for Healthcare Research and Quality. Fact Sheet. In: CAHPS® and the National CAHPS® Benchmarking Database (AHRQ Publication No. 00-PO47). Rockville, MD: Agency for Healthcare Research and Quality; Apr 2000. URL: http://www.ahrq.gov/qual/cahpfact.pdf

38. Tarlov AR, Ware JE, Greenfield S, Nelson EC, Perrin E, Zubkoff M. The Medical Outcomes Study. An application of methods for monitoring the results of medical care. JAMA 1989 Aug 18;262(7):925-930. [Medline: 89329130] [doi: 10.1001/jama.262.7.925]

39. ; The Foundation for Accountability. FACCT Diabetes Survey. Portland, OR: The Foundation for Accountability; 1999.

40. ; Bureau of Labor Statistics. Current Population Survey. URL: http://www.bls.gov/cps/home.htm [accessed 2002 May 22]

41. Cronbach LJ. Coefficient alpha and the internal structure of tests. Psychometrica 1951;16:297-334.

42. ; SPSS Inc. SPSS. Version 9. URL: http://www.spss.com/ [accessed 2003 Dec 26]

43. Dawson-saunders B, Trapp RG. Basic and Clinical Biostatistics (Lange Medical Books). Norwalk, CT: Appleton & Lange; Jan 15, 1994.

44. Gallagher PM, Fowler FJ, Stringfellow VL. The nature of nonresponse in a Medicaid survey: causes and consequences. Nonresponse in federal household surveys: new measures and new insights. Presented at: International Conference on Survey Nonresponse; 1999; Portland, OR URL: http://www.jpsm.umd.edu/icsn/papers/Gallagher.htm

Abbreviations

BRFSS: Behavioral Risk Factor Surveillance Survey
NHIS: National Health Interview Survey
US: United States

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<u>Original Paper</u>

Experience and Attitudes towards Information Technology among First-Year Medical Students in Denmark: Longitudinal Questionnaire Survey

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Abstract

Background: As more and more information technology (IT) resources become available both for support of campus- based medical education and for Web-based learning, it becomes increasingly interesting to map the information technology resources available to medical students and the attitudes students have towards their use.

Objective: To determine how extensively and effectively information handling skills are being taught in the medical curriculum, the study investigated Internet and computer availability and usage, and attitudes towards information technology among first-year medical students in Aarhus, Denmark, during a five-year period.

Methods: In the period from 1998 to 2002, students beginning the first semester of medical school were given courses on effective use of IT in their studies. As a part of the tutorials, the students were asked to complete a web-based questionnaire which included questions related to IT readiness and attitudes towards using IT in studies.

Results: A total of 1159 students (78%) responded. Overall, 71.7% of the respondents indicating they had access to a computer at home, a number that did not change significantly during the study period. Over time, the power of students' computers and the use of e-mail and Internet did increase significantly. By fall 2002, approximately 90% of students used e-mail regularly, 80% used the Internet regularly, and 60% had access to the Internet from home. Significantly more males than females had access to a computer at home, and males had a more positive attitude towards the use of computers in their medical studies. A fairly constant number of students (3-7%) stated that they would prefer not to have to use computers in their studies.

Conclusions: Taken together with our experience from classroom teaching, these results indicate optional teaching of basic information technology still needs to be integrated into medical studies, and that this need does not seem likely to disappear in the near future.

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Introduction

Software for computer-assisted learning (CAL) in medicine has been available from the 1960s, or almost as long as computers. Results of evaluations of software for teaching and learning in medicine vary considerably, largely because of differences in the learning situations and in the evaluation design [1-5]. In spite of the early awareness of the potential of CAL programs among dedicated educators, production and marketing of a substantial amount of programs started only after the multimedia computer became readily available in the mid-1990s.

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With the increased availability and speed of the Internet come new ways of disseminating interactive multimedia learning modules and possibilities for integrating information and communication technologies into other methods of teaching and learning.

The approach of many teachers and course directors in traditional universities has been to "wait and see." A growing number of enthusiasts, however, have tried to implement new ways of teaching and learning using, or facilitated by, information technology (IT), and in many cases integration of information and communication technology (ICT) has been used to support changes in teaching and learning methods.

The approach of students, whose motivation is usually exams, could also be characterized as "wait and see." The question is how long to wait and then what to look for. Access to computers, at home and on campus, and Internet access are both important. The issue of students' IT literacy, however, may be even more important. It is often thought that it is only a matter of time until all young students become skilful in the use of computers, and IT training is no longer necessary in higher education. The present study was conducted to test this hypothesis and to determine whether students entering medical school already had all the IT skills they would need to use IT effectively during their medical studies. Analysing IT skills is especially difficult when comparing results over a span of years: what would be seen as a trivial task today may have required advanced knowledge five years ago. Consequently, instead of skills, the study investigated computer availability and attitudes and how these measures might be interrelated. Several previous studies have addressed the issue of IT literacy among medical students, typically through questionnaires given in one or a few semesters [6- 14]. The present study, extending from the 1998 fall semester to the 2002 fall semester, revealed developments over a five-year period that was characterized by an unforeseen expansion in IT and Internet availability throughout the Western world.

We asked medical students about their access to IT, their attitudes and interests in using IT as part of the medical studies they had just started. The purpose was to clarify when and where IT could be effectively integrated and what IT training and hardware needs could be expected.

Methods

In the period from 1998 to 2002 (nine semesters), students beginning the first semester of medical school in Aarhus, Denmark, were given two lectures and three group-based tutorials on effective use of IT in their studies. As a part of the tutorials, the students were asked to complete a questionnaire (seAppendix 1). This Web-based questionnaire was completed 2 to 3 weeks after start of studies, and included questions related to IT readiness and attitudes towards using IT in studies. The questionnaire was set up using Coldfusion [15] on a Windows 2000 www-server. Data were entered into an open database connectivity (ODBC) database and were analysed using Microsoft Excel. Teachers were present during the input phase to answer technical questions.

The students were asked their age and sex; whether they had access to a computer at home and whether it was PC, Macintosh, or other; which operating system it used; the amount of RAM; the processor type; and whether the computer had a soundcard, a CD drive, or a modem attached. Students were also asked whether they had access to the Internet and e-mail from home, and the frequency of usage. Finally, the students were asked the following questions about their attitudes towards IT in the medical school.

1. Would you like to use the computer for calculations and reports?
2. Would you like to use the computer as a supplement to teaching?
3. Would you like to use the computer as a replacement for some of the theoretical teaching?
4. Would you like to be able to ask questions to teachers via e-mail?
5. Would you like to be able to use the computer for distance learning from home?
6. Would you prefer that you *did not* have to use the computer during your medical studies?

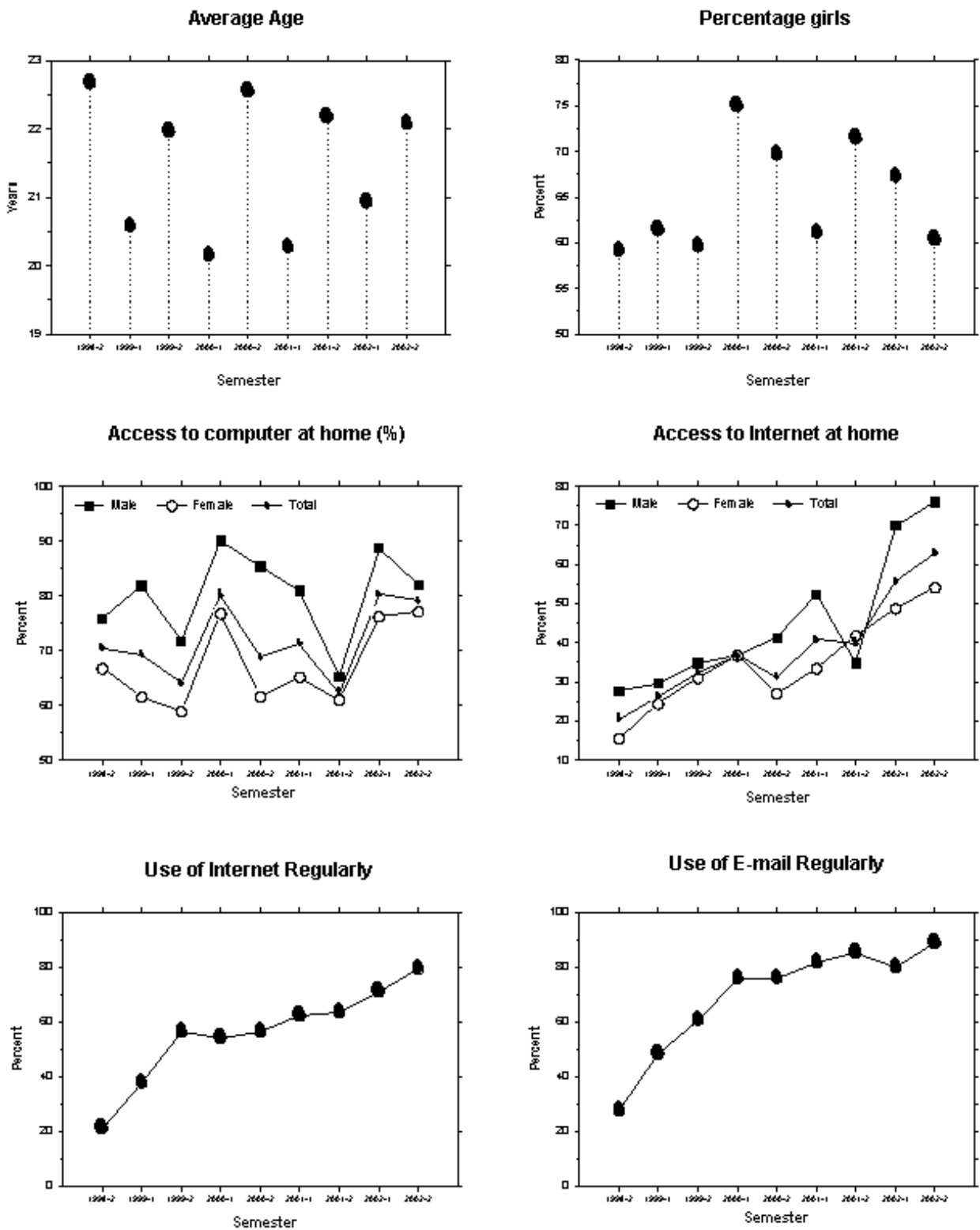Minor additions to answering options were made as new processors and operating systems became available.

The X^2 test was used to compare frequencies.

Results

Basic data

Of 1474 medical students who started their studies between fall 1998 and fall 2002, 1159 (78.6%) completed the Web-based questionnaire. The average age was 21.6 years (Figure 1b). Students beginning in the summer were, on average, 2 years older than those beginning in winter, which is a result of the way students are accepted for medical studies in Aarhus. Of all participating students, 60.3% were female. Distributions for semesters are given in Figure 1a and Figure 1b. A total of 71.7% of all students (79.7% of males; 67.5% of females) indicated they had access to a computer at home. There were substantial fluctuations from semester to semester (Figure 1c), but comparing the average of the first four semesters with the average of the last four revealed only a slight increase from 70.9% to 73.1% (NS). The increase from 70.4% in fall 1998 to 79.3% in 2002 was not statistically significant. Internet access from home increased from 20.4% to 62.9% (p < 0.001) in the study period, and there was an even more pronounced increase in the use, from any location, of Internet and e-mail (Figure 1e and Figure 1f). It is especially significant that, although the university did not require the students to use e-mail, by the end of the study period, 88.7% of all students used e-mail regularly.

Figure 1. Distribution of age and gender (a, b) and computer, Internet, and e-mail usage (c to f). Spring semesters are indicated with *1*; fall semesters with *2*. Use of Internet and e-mail was graded as never, rarely, regularly, often, or daily. The curves sum up answers: regularly, often, and daily

Computers used

Not surprisingly, the power of computers increased in the study period (Figure 2a). The incidence of soundcards in computers available to students increased from 48% to 71% (p < 0.001), the incidence of CD drives in home computers increased from 52% to 76% (p < 0.001), and of modems from 27% to 59% (p < 0.001).

Among medical students in Denmark, Macintosh computers are not in common use. Numbers decreased from about 3 to 4% at the start of the study period to about 0 to 1% in the last part (Figure 2b).

Attitudes

Males were significantly (p < 0.001) more interested in replacing traditional with ICT- supported teaching and learning. An

average of 46.6% of males versus 21.8% of females indicated that they would like to replace traditional teaching with use of computers if possible. Despite fluctuations, there was no trend towards a consistent change in these numbers during the study period (Figure 2c).

A small percentage (6.8% of females and 3.3% of males) indicated that they would prefer not to have to use a computer during their medical studies. Again, in spite of fluctuations, there was no trend towards a consistent change in this number (Figure 2d).

The difference between males and females in attitudes towards use of distance education was also highly significant ($p < 0.001$): 38.7% of males versus 19.9% of females indicated a positive attitude (Figure 2e).

The attitude towards use of ICT resources as a supplement was more positive than for ICT replacement or for distance education (86% of boys and 76% of girls were positive, Figure 2f)

Figure 2. Type of computer (a, b) and attitudes towards use of computer (c to f). Spring semesters are indicated with *1*; fall semesters with *2*. As might be expected, the number of powerful computers among students was increasing; The percentage of Macintosh computers was decreasing. 6.8% of females answered that they would rather not use a computer as part of the study. The corresponding percentage for males was 3.3%

Discussion

Use of IT as a tool to support medical teaching and learning was introduced gradually over several years at The University of Aarhus, without a well-defined strategy. Similar trends have been reported from many other universities. One reason may be the great diversity of IT skills among both teachers and students. There may also be a general reluctance to change educational methods and a belief that available IT resources would not enhance learning. Many things changed during the period of this study. Many medical schools have moved towards problem-based learning. Implementation of computer-supported collaborative learning [16] has driven IT investments and implementation in some schools, and certainly the value of available Internet resources and of e-communication in supporting medical learning can no longer be denied. At the University of Aarhus, which is a typical research-intensive institution, educational methods have undergone an evolution rather that a revolution and IT has not been considered a driving force for pedagogical change. Still, project work and other study areas that rely heavily on medical literature available through the Web have demonstrated the need for a minimum of IT literacy among the students, and it is important to know roughly the number of students in need of special IT courses.

This study shows that an average of 71.7% of new medical students had access to a computer at home. The number was significantly higher among males, and showed considerable fluctuations from semester to semester, but did not increase significantly in the study period (between 1998 and 2002). When compared to German study from 1992 by Gunther Eysenbach, however, this study shows a significant increase in IT availability and knowledge [17].

Approximately 79% of registered students completed the questionnaire. The seminar included a number of important practical issues, such as a general introduction to the use of the university's IT facilities. We encouraged all participants in the seminars to complete the survey, but did not record reasons for not completing it. In principle, the 21% of registered students who did not complete the questionnaire might have different attitudes towards IT and their access to computers at home might differ from those who completed the survey. If this was the case, absolute numbers might be slightly biased. We do, however, assume that failure to complete the survey would be fairly constant during the study period, and thus relative developments with time would be unaffected by the missing questionnaires.

As noted, students beginning medical studies in the summer were an average of 2 years older than those beginning in the winter. A comparison of computer availability with age, revealed a U-shaped curve: ~80% at 19 years, ~60% at 22 years, and ~88% at 26 years. Changes in computer availability during the study period therefore can probably be attributed, at least in part, to fluctuations in age. Fluctuations in the percentage of females accepted could also be expected to influence computer availability over years. A comparison of Figure 1b and Figure 1c, however, does not show a consistent trend.

The most comprehensive study of IT literacy conducted in European universities is probably the Survey of European Universities Skills in ICT of Students and Staff (SEUSISS) project, funded under the EU-Socrates Minerva Programme. The consortium, which includes seven universities from the UK, Finland, Norway, The Netherlands, Italy, France, and Spain, gathered data in 2001 and 2002 in a continuation of a 10-year University of Edinburgh data collection project [18,19,20]. Although the present study included only medical students, many of the questions related to IT literacy can be expected to apply to all students in higher education, with the exception of students in computer science and related areas.

Questions that remain important in the present study and in the SEUSISS and Edinburgh studies are:

- What are the developments in *general IT literacy*, computer availability at home, and general availability to IT, and can we expect that problems with IT literacy will disappear with time?
- Can university teachers and administrators expect that *e-communication* will reach all students?
- Are *gender differences* in IT attitudes and literacy significant and do these differences tend to change over time?

General IT literacy

Roughly half of all students had access to a home-PC with a CD, soundcard, and sufficient computing power and RAM to effectively run modern multimedia applications. Whereas access to *any* PC at home showed only a very small increase, access to a "modern multimedia PC" increased from about 30% to about 65%. In the SEUSISS project (2001-2002), the numbers for PC ownership at the start of studies varied from 54% (Åbo, Finland) to 89% (Groningen, the Netherlands). In Edinburgh by 2000, ownership was at 44% for males and 37% for females, and the Edinburgh study reports that this gender gap diminished with time. The data from this study seem to be consistent with the other European data, although the gender differences in this study did not decrease, and no distinction was made in this study between ownership and availability of IT at home. Availability of a powerful PC at home is increasing, but a substantial proportion of new students still do not have access to a computer at home, and it is still too early to predict that they will within the next few years.

The Edinburgh study reports about 8% Macintosh users, and a slight trend towards more Macintosh users among women. Medical students, like most other computer users in Denmark, use PCs almost exclusively.

It is one thing is to own a PC or to have access to one, quite another is to possess IT skills and to be IT literate. A dramatic increase in IT literacy might be expected during these years when IT and Internet use have increased generally. Data on Internet availability are continuously monitored by the European Union, and their data show that Denmark is one of the three leading countries with respect to IT use and Internet spread [21].

In the present study, direct measures of IT-literacy were not identified, and no attempt was made to test the students in this respect. However, it seems reasonable to expect a correlation

between attitudes towards IT and IT literacy. Indeed in hands-on courses a small percentage of students were found to be absolute novices with respect to computer use. Between 3 and 7% of the students (significantly more females than males) who indicated that they would prefer not to have to use computers in their studies. The consistency of this finding, corroborated in several earlier studies [7,8,9,14,18], suggests there is a need for training in basic IT and information-handling skills as an optional element in medical training [22]. Moreover, this study does not suggest this need is likely to disappear in the near future.

E-communication

Use of Internet and e-mail increased dramatically during the study period. The curve for e-mail, in approaching 100%, shows a decreasing slope, while the curve for Internet use indicates that a further increase above 80% can be expected. An interesting question is whether these numbers will increase to 100%. At present, the university does not use e-mail and Internet as a mandatory route of communication with or among medical students, but the numbers presented here indicate that the time may be ripe to start doing so. Several universities around the world have successfully started using e-mail as a mandatory communication, and the Internet as a mandatory information and communication channel. Although a small number of students and teachers may experience going from paper-based to e-communication as a drastic step, this study shows that it will probably not be a problem for the vast majority, and that the minority will meet only temporary difficulties.

Gender differences

This study has revealed significant gender differences both in access to computers and in readiness to integrate IT in the learning process. As an example, roughly 50% of males versus 25% of females responded that they would like to replace some traditional teaching with IT-based activities.

In these respects, the study correlates directly with the 10 year follow-up study from Edinburgh [18,19]. The results are interesting in a number of ways when it comes to planning, developing, and implementing ICT-supported learning activities. Communications with the medical students indicate that most female students are not directly opposed to ICT-supported teaching and learning; however, female students may be more pragmatic and more focused on exams, whereas some male students may favour the freedom of time and space offered by e-learning.

Conclusions

During the five years of this study there was a dramatic increase in availability of IT resources. It can be considered positive when about 30% of students indicated that they would like to exchange traditional learning for e-learning, and about 80% indicated that would like to use ICT resources as a supplement. Some course directors and teachers are still reluctant to increase the importance of IT support in the studies, but this study indicates that most students are ready to change. There is still a need for teaching in basic IT as part of medical study, and this need does not seem likely to disappear in the near future.

Conflicts of Interest

None declared.

Multimedia Appendix

Web-based Questionnaire: [HTML File, 20KB - jmir_v6i1e10_app1.html]

References

1. Atkins, O'Halloran. Evaluating multimedia applications for medical education. In: AMEE Guide No 6: Association for Medical Education in Europe; 1995. URL: http://www.amee.org/%5BAMEE%5D

2. Alexander S, McKenzie J. An evaluation of information technology projects for university learning. In: AMEE Guide No 6. Canberra: CUTSD, Commonwealth of Australia; 1998. URL: http://www.dest.gov.au/archive/cutsd/publications/%5BCUTSD%5D

3. Hovenga EJ. Using multi media to enhance a flexible learning program: lessons learned. Proc AMIA Symp 1999:530-534 [FREE Full text] [Medline: 20032925]

4. Brady Boyce Ba, Winne MD. Developing an evaluation tool for instructional software programs. Nurse Educ 2000 May;25(3):145-148. [Medline: 11111571] [doi: 10.1097/00006223-200005000-00015]

5. Dørup J. Educational technology as a scientific discipline. In: Haux R, Kulikowski C, editors. Yearbook of Medical Informatics. Stuttgart: IMIA; 2002:533-535 URL: http://www.dest.gov.au/archive/cutsd/publications/%5BCUTSD%5D

6. Bresnitz EA, Stettin GD, Gabrielson IW. A survey of computer literacy among medical students. J Med Educ 1986 May;61(5):410-412. [Medline: 86200102]

7. Crowe P, Howie C, Thorpe M. Self-reported computer literacy of medical students and staff: good facilities are not enough. Med Teach 1998;20(3):264-265 [FREE Full text] [doi: 10.1080/01421599881057]

8. Gouveia-oliveira A, Rodrigues T, De Melo FG. Computer education: attitudes and opinions of first-year medical students. Med Educ 1994 Nov;28(6):501-507. [Medline: 95166065]

9. Jones RB, Navin LM, Barrie J, Hillan E, Kinane D. Computer literacy among medical, nursing, dental and veterinary undergraduates. Med Educ 1991 May;25(3):191-195. [Medline: 91312228]

10.   Koschmann T. Medical education and computer literacy: learning about, through, and with computers. Acad Med 1995 Sep;70(9):818-821. [Medline: 95398748]

11.   Nurjahan MI, Lim TA, Foong A, Yeong SW, Ware J. Computer literacy in medical students. Med Educ 2000 Nov;34(11):966. [Medline: 20561287] [doi: 10.1046/j.1365-2923.2000.0818i.x]

12.   Sancho JJ, González JC, Patak A, Sanz F, Sitges-serra A. Introducing medical students to medical informatics. Med Educ 1993 Nov;27(6):479-483. [Medline: 94268339]

13.   Stringer J, Moreno EA. A computer literacy requirement for medical students. Acad Med 1996 May;71(5):522. [Medline: 20140661]

14.   Peroz I, Bösel C, Lange KP. Representative survey of dental students about the present state of education, PC equipment and configuration requirements for a net-based dental education system. Med Teach 2003 Jul;25(4):385-390. [Medline: 22775696] [doi: 10.1080/0142159031000136761]

15.   ; Macromedia. Macromedia.com. URL: http://www.macromedia.com/ [accessed 2004 March 5]

16.   Kumar VS. Computer-supported collaborative learning: issues for research. URL: http://www.cs.usask.ca/grads/vsk719/academic/890/project2/project2.html [accessed 2004 March 5]

17.   Eysenbach G. Computereinsatz und Computerkenntnisse unter Medizinstudenten [Computer use and computer literacy among medical students]. Informatik, Biometrie und Epidemiologie in Medizin und Biologie 1995;26(1):56-66 [FREE Full text]

18.   Asgari-jirhandeh N, Haywood J. Computer awareness among medical students: a survey. Med Educ 1997 May;31(3):225-229. [Medline: 97374694]

19.   Macleod H, Haywood D, Anderson C. Gender & ICT-a 10-year study of new undergraduates. URL: http://homepages.ed.ac.uk/jhaywood/papers/techtrends.pdf [accessed 2004 March 5]

20.   Survey of European Universities Skills in ICT of Students and Staff. URL: http://www.intermedia.uib.no/seusiss/results.html [accessed 2004 March 5]

21.   Europa: European Information Society. URL: http://www.europa.eu.int/information_society/eeurope/2002/benchmarking/list/2001/index_en.htm [accessed 2004 March 5]

22.   Dørup J, Schacht Hansen M, Ribe LR. Integrating IT-supported and traditional learning in a Health Informatics course. In: Ribeiro LM, Marques dos Santos J, editors. Proceedings of the 8th International EUIS Conference. Porto; Jun 19, 2002:106-107 URL: http://www.intermed.dk/contentmanagement/itfacilitation.pdf [accessed 2004 March 5]

Abbreviations

CAL: computer assisted learning

EU: European Union

IT: information technology

ICT: information and communication technology

ODBC: open database connectivity

RAM: random access memory

SEUSISS: Survey of European Universities Skills in ICT of Students and Staff

Original Paper

A Multimedia Interactive Education System for Prostate Cancer Patients: Development and Preliminary Evaluation

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Abstract

Background: A cancer diagnosis is highly distressing. Yet, to make informed treatment choices patients have to learn complicated disease and treatment information that is often fraught with medical and statistical terminology. Thus, patients need accurate and easy-to-understand information.

Objective: To introduce the development and preliminary evaluation through focus groups of a novel highly-interactive multimedia-education software program for patients diagnosed with localized prostate cancer.

Methods: The prostate interactive education system uses the metaphor of rooms in a virtual health center (ie, reception area, a library, physician offices, group meeting room) to organize information. Text information contained in the library is tailored to a person's information-seeking preference (ie, high versus low information seeker). We conducted a preliminary evaluation through 5 separate focus groups with prostate cancer survivors (N = 18) and their spouses (N = 15).

Results: Focus group results point to the timeliness and high acceptability of the software among the target audience. Results also underscore the importance of a guide or tutor who assists in navigating the program and who responds to queries to facilitate information retrieval.

Conclusions: Focus groups have established the validity of our approach and point to new directions to further enhance the user interface.

Introduction

There is hardly a more-distressing health event in a person's life than receiving a cancer diagnosis. Such a diagnosis often has been compared with a "blow to the head," or the feeling that the "world has changed forever." Often, intense feelings of anxiety and fear about oneself and the future of family members are triggered by a cancer diagnosis. Yet, to make informed decisions about their health care during this time of high distress, patients and their family members need to process complicated medical information that is fraught with medical and probabilistic terms.

This is particularly true for men diagnosed with early-stage prostate cancer (ie, tumors confined to the prostate without involvement of regional lymph nodes or distant metastasis). Although prostate cancer is a highly-treatable disease with an average survival rate of 97% over 5 years [1], there is no one standard treatment that is appropriate for every patient [2,3]. Patients usually have the choice between surgical removal of the prostate (ie, prostatectomy), external beam radiation, or implantation of radioactive seeds. Watchful waiting, or close

monitoring of disease progression through frequent prostate specific antigen (PSA) levels and digital rectal examinations (DREs), is sometimes an option. In addition, patients' treatment decision making is further complicated by the tendency of physicians to recommend treatment options that represent their medical specialty [4]. Thus, newly-diagnosed prostate cancer patients not only have to cope with the emotional impact of the diagnosis, but also have to make sense of complicated medical-treatment information, resolve often-times diverging medical opinions about how to best treat the disease, as well as to anticipate potential unpleasant treatment-related side-effects (ie, incontinence and erectile dysfunction [5]).

In recognition of these unique patient-information needs the primary aim of this paper is to describe the development and preliminary evaluation of a novel and innovative computer-based multimedia prostate interactive education system (PIES) and treatment-decision tool. We will begin with a brief overview of the most-common treatment options for prostate cancer and their likely consequences for quality of life. Second, we will describe how patients' information-seeking behavior has changed with the development of personal computers and the Internet. Third, we will place the development of PIES in the larger context of computer-aided learning. Fourth, we provide a detailed description of PIES and a report of its preliminary evaluation through focus groups. The paper closes with recommendations for further developments of computer-based education systems and decision tools.

Computer-Aided Learning

Since the invention of the electronic computer there have been 2 divergent opinions as to how this device should be used. One group saw the computer's principal use as a number manipulator, an extensive, ultrafast, and accurate calculator. Another group envisioned the computer as a symbol manipulator that might be taught to use logic and make decisions in a human fashion. The symbol-manipulation group eventually founded the discipline called artificial intelligence (AI). As time passed, artificial intelligence spawned many subdisciplines such as robotics, natural language recognition, and expert systems. The driving force behind expert-system development was the attempt to program a computer so it could "think" and make human-like decisions. A generally-accepted definition of an expert system is one that performs at or near the level of a human expert in a particular field of endeavor [6].

The first large expert system to perform at the level of a human expert was developed for use in the health care field [7]. This system, called MYCIN, was developed at Stanford University in the mid 1970s. The MYCIN program was designed to provide physicians with advice about bacteremia and meningitis; it emulated the expertise from a physician specializing in these infections. MYCIN asks the physician, who is requesting its advice, several questions. Additionally, it requires personal data about the patient and will ask for results of laboratory tests when it needs this information to aid in its analysis process. After analyzing patient information and data, MYCIN makes a diagnosis as well as a drug-therapy recommendation. MYCIN also has the ability to explain how it arrived at its diagnosis [8].

The architecture of the MYCIN program consists of 2 major, distinct elements: (1) a knowledge base and (2) an inference engine. The knowledge base contains the facts and heuristics necessary to derive medical analyses of bacteremia and meningitis infections. The inference engine contains the inference mechanisms and control strategies employed by MYCIN to derive the diagnosis and treatment recommendation. It soon became clear that this architecture was not just specific to MYCIN but could be used as a template or "shell" for encoding and applying expertise in any field.

Computer-Aided Learning for Educational Purposes

One of the most interesting applications of expert system technology is for education. One goal among some artificial-intelligence researchers has been to develop a computerized tutor that performs at the level of an excellent human tutor. The resulting computer program that achieves this objective would be called an intelligent tutoring system (ITS). The effort to create truly-intelligent computer-based tutors has been underway for many decades [9]. Ultimately intelligent tutoring systems attempt to simulate the behavior of an intelligent human tutor in addition to acting as a domain expert. The characteristics of an intelligent tutoring system include the ability [10,11] to:

1. teach a given subject
2. detect student errors
3. analyze where and how the student made an error
4. correct flaws in the student's logic
5. clear up any misgivings or misunderstandings the student may have about the material.

Although the development of expert systems for training has been moderately successful and other kinds of expert systems, such as income-tax preparation assistants, have been extremely successful commercially, intelligent-tutoring-system development did not advance significantly for several years after its initial efforts. It is within the last decade that prospects for intelligent tutoring systems have shown promise. Advancements in hardware, operating systems, and interactive-multimedia development tools have created a software environment that makes real intelligent tutoring systems a possibility [12- 14].

Interactive multimedia software is already playing a key and unique role in the educational process. It is used as a stand-alone educational module that is intended to enable an interested individual to learn about a particular topic or subject [15]. It has been used as a supplement to classroom presentations [16,17] and laboratories [18,19], and it is used as a dynamic textbook [20]. Recently, interactive multimedia have been integrated with expert-system technology, producing highly-interactive intelligent tutoring systems [21- 25]. These intelligent tutoring systems "learn" about the individual student and can tailor the material to meet the needs and the learning styles appropriate to the individual student.

Computer-Aided Learning for Health Care

One of the first successful large-scale expert systems was developed for diagnosis and treatment of certain infections [26]. The principles of this approach were subsequently applied to

include the application of artificial intelligence techniques to medical diagnosis (for example, [27- 32]). Artificial intelligence research within medicine is very active today although attempts to develop physician-like diagnostic systems have waned. Instead, these systems are now geared to assist students and physicians to develop and hone diagnostic skills.

Because enthusiasm for medical diagnosis systems that would "assist" physicians and might even dispute their diagnoses was tepid, the development of systems designed for practitioner education has been advanced. Consequently, considerable effort has been made to produce software systems that could simulate medical situations and include a computerized mentor that would assist learners in their decision-making process. The rapid development of computer hardware has eliminated many of the early problems encountered in developing medical-training expert systems. Today's graphical user interfaces coupled with developments in various video and audio digital circuit boards have encouraged the development and use of multimedia software. Multimedia is usually defined as "the use of a computer to present and combine text, graphics, audio and video with links and tools that allow the user to navigate, interact, create, and communicate" [26]. Multimedia programs have been written to help educate medical practitioners in almost every aspect of health delivery. Systems exist to train and educate individuals in the principles of: laparoscopic procedures and epilepsy diagnosis and treatment [33], ureterorenoscopy [34], hysteroscopy [35], dermatology [36], diabetes management [37], communicable and rare diseases [11], red cell antibody identification [38], cervical cytology [39], psychotherapy [40], and many other health-related areas.

Besides educating practitioners, progress has been made recently in developing interactive multimedia software products for patient use and education. Agre et al, reporting on a project that develops a CD-ROM for cancer-related patient education [41] notes that CD-ROMs are more valuable for learning than booklets or videotapes. The study finds that CD-ROM technology allows for greater depth in content and has the ability to satisfy a broad range of educational needs. Guendelman et al [42] have used a computer-based self-management program called Health Buddy to enable children to assess and monitor their asthma symptoms and quality of life as well as to transmit this information to health care providers. Using a randomized control trial, 66 individuals were placed in the intervention group while 68 were in the control group. The study found that compared with an asthma diary, monitoring asthma symptoms and functional status with the Health Buddy increases self-management skills and improves asthma outcomes. Another recently-developed CD-ROM focused on the education of children with leukemia (ages 4-11) and their families about the disease and its treatment [43].

Multimedia has also been used, with some success, for educational intervention for low-education, low-income Latinas [44]. At the conclusion of the study, it was found that about 40% of the women that had scheduled or received mammography had attributed their decision to the intervention. Interactive multimedia has been used to deliver information: about self-medication [45], for patient colonoscopy education [46], for genital herpes education [47], for personal care of

diabetes [48], for skin cancer prevention [49], for nutrition screening and counseling [50], for hypertensive patients [51], and for numerous other diseases or treatments.

Gustafson et al have developed a computer-based health information and support system [52,53]. This Comprehensive Health Enhancement Support System (CHESS) is a Web-based support system that includes modular programs on breast cancer, AIDS/HIV infection, sexual assault, alcoholism, and academic crisis. For example, the breast cancer module provides disease information, a treatment decision aid, an opportunity to contact health care providers via e-mail, testimonials from patients, and a patient forum to exchange information and to solicit social support. Evaluation studies have confirmed that the CHESS system is user-friendly and well accepted by patients of diverse demographic background [54]. The use of the CHESS system has also been linked to improvements of quality of life, and increased participation in health care among HIV-positive patients [54]. Despite its sophistication, the CHESS system lacks the capacity to present information in a targeted and tailored manner based on specific patient characteristics.

Computer-Aided Tailored Patient Education

A decade ago researchers [10] noted that computer software has the potential to elicit information from patients and to use this information to tailor patient education. Because the literature is not always consistent in the use of the terms *targeted* and *tailored* with respect to health communications, a recent article has suggested clarification and standardization in terminology [55]. The authors suggested that health communications be labeled as targeted if they are directed towards a particular subgroup of the population, and to use the term tailored if the information is designed to address individual characteristics of a person. Both targeting and tailoring depend on the assessment of group or individual characteristics that have been derived from prior data collections [55].

The goal of targeting and tailoring health communications is to increase the personal relevance of the message to the individual. Research has demonstrated that messages that are relevant to the person are better understood and better remembered [56,57]. In addition, personally-relevant messages are also more likely to lead to behavior change [58]. Thus, it is generally expected that an individual will react to tailored messages with increased attention, improved understanding, and an increased tendency for behavior change [54,59].

Methods

Overview of the Prostate Interactive Education System (PIES)

The prostate interactive education system (PIES) is an interactive multimedia expert system that is being developed to help patients who have been diagnosed with early-stage prostate cancer. PIES provides the patient with a multitude of treatment information and encourages patients to obtain the kind of information that they desire about the disease. PIES is envisioned as an important step in the treatment-decision process. The software will enable a patient to follow a logical decision process and obtain the information he needs at his

current state of decision-making. The software will prepare a factual report for a psychologist who will meet with the patient following his interaction with the software. The temporal placement of the software is shown in Figure 1. Once the patient is diagnosed with prostate cancer, he is offered the PIES software package to assist him in making a treatment decision. PIES provides additional information and does not preclude a second opinion, as shown in Figure 1. In fact, the patient may receive a second opinion before using PIES.

Figure 1. Role of prostate interactive education system (PIES) in the treatment decision process
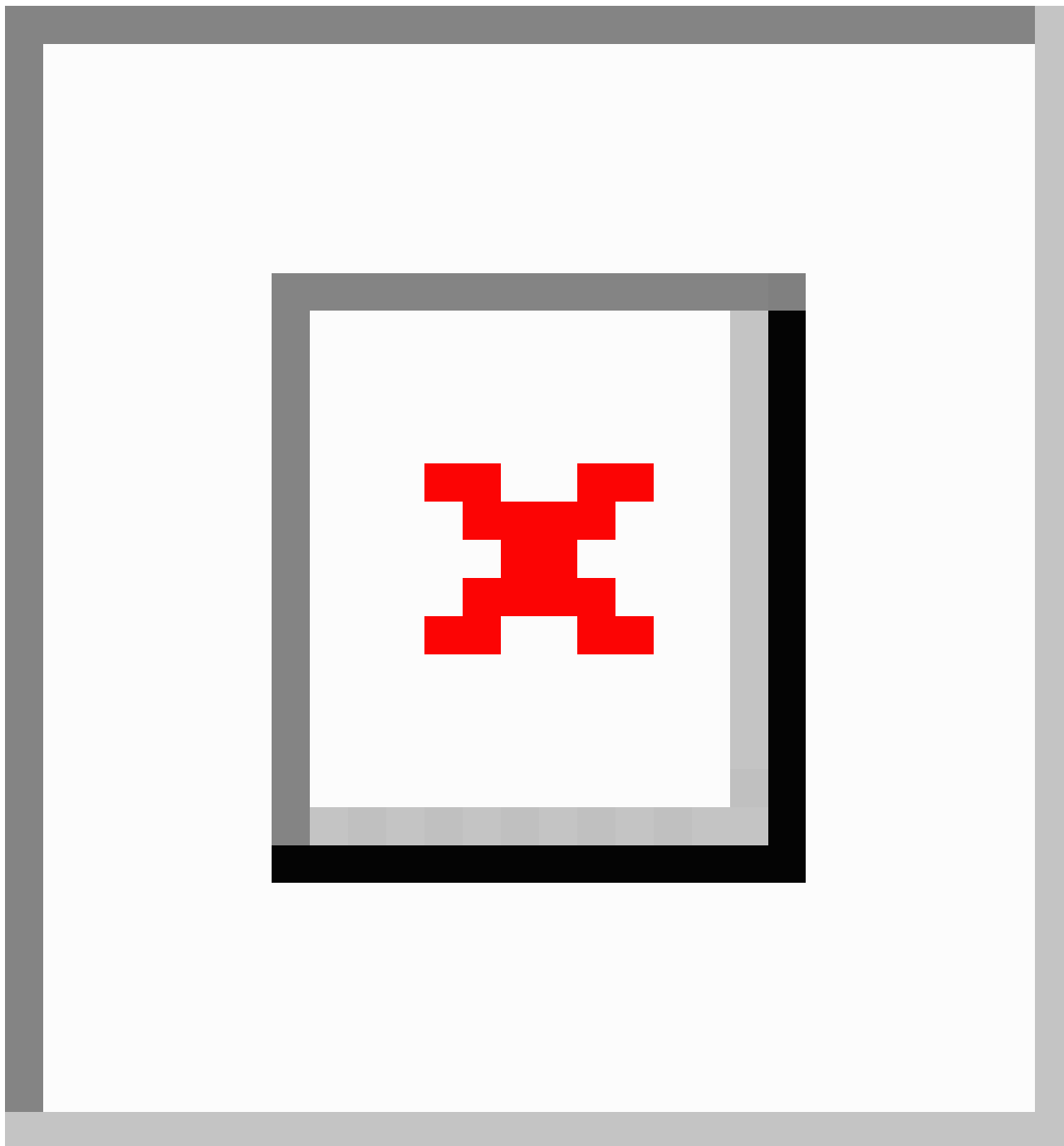
The purpose of the PIES software is threefold:

1. It allows a patient to obtain the information he wants in a quiet environment. The patient interacts at his own speed. Questions can be asked in any order. Multiple physicians are consulted without any implied obligation on the patient's part. A patient may consult with a surgeon and a radiologist. Consequently, the patient can gather information in a nonthreatening and unpressured environment.

2. It allows the patient to access the experiences of other patients. An extensive library of interactive videos of others' experiences will be available to the patient. The patient can choose to hear from videotaped actual patients who are in the same age group, of the same race, and who had a particular treatment.

3. It provides an expert system that will be operating in the background. The expert system will analyze what the patient is doing and determine if the patient is getting enough

information to make an informed decision. The expert system will not make any decision for the patient. It will only follow and evaluate the completeness of the process. If the expert system becomes concerned that the patient is not being thorough in his examination of alternatives, it will make suggestions to view information that has not been accessed and about where the patient might find it. The patient can follow or ignore the expert system's suggestions.

PIES is not a diagnosis tool. Nor does it give advice in the form of "this is what you should do." Instead, it allows patients to ask questions and get information by interacting with a multimedia computer program. The multimedia program allows a patient to visit a library to get up-to-date information about prostate cancer and its treatment. The patient will be able to interact with virtual physicians who can answer specific questions that the patient may have. Various physicians (eg, surgeons, radiologists) can be queried by the patient. The physicians "consult" with the patient through digital video sequences as well as through interactive multimedia question-and-answer sessions. The patient will also be able to "visit" a virtual support room where he will have the chance to

listen to other patients talking about the disease and how they determined their own course of treatment. Support group members also discuss dealing with the side effects of their treatment. The patient will also be able to consult with a virtual sex therapist who will discuss methods and assistive technologies that will enable them to continue sexual activities. Finally, each patient will be provided with a decision aid that will assist him in treatment decision making.

An overview of the PIES architecture is shown in Figure 2. The patient interacts with the CD-ROM based system on a personal computer. The system is CD-ROM based but could be made available over the Internet. A CD-ROM delivery system was chosen so that those patients without a high-speed connection to the Internet would not experience delays caused by downloading videos. The information is developed and presented using Macromedia's Authorware [60]. Authorware is able to communicate with other software and can transmit information in real time or near real time. Authorware will allow the patient to have access to other programs such as a notebook to record information, and various applicable medical-applications software.

Figure 2. The PIES architecture
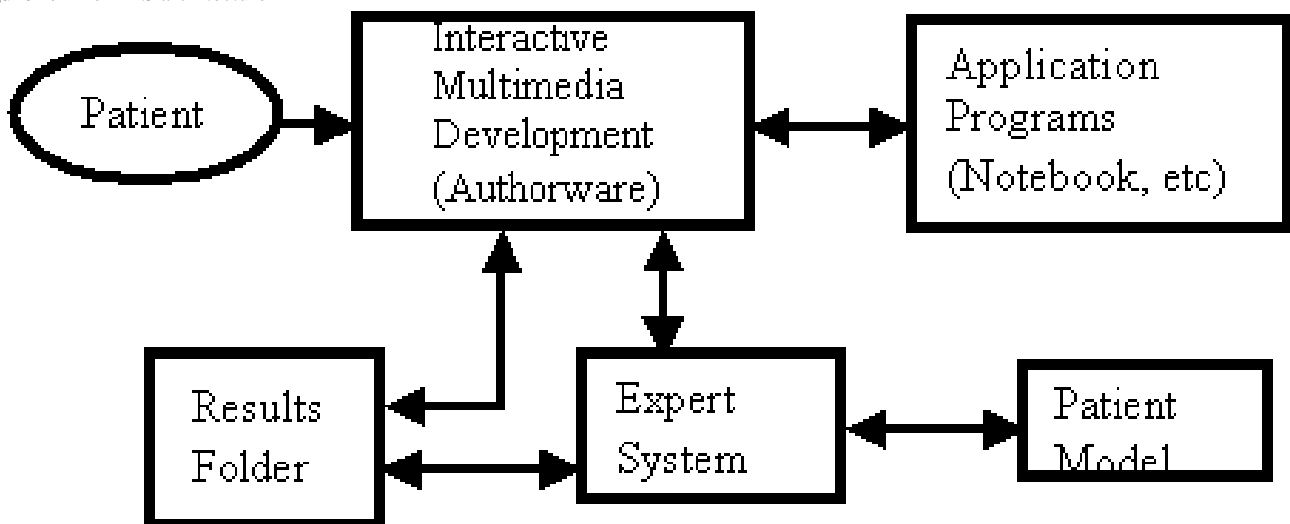
The patient model, described later, is a computer characterization of the patient; it is changed dynamically by the expert system. In turn, the expert system, also described later, analyzes how the patient interacts with the software and reports this in the results folder. The results folder contains information that the expert system will use to generate a report to the psychologist.

The paradigm used in PIES is that of a patient entering a health center. When the patient enters PIES, he is greeted by an information specialist. The information specialist welcomes the patient and shows him around the PIES Health Center. The Health Center consists of a reception area, a library, and a group meeting room on the first floor, and physician offices on the second and third floors, connected through an elevator. Each room is interactive and the patient is shown how to use the room's facilities when he first chooses to enter the room. After showing the patient the Health Center layout, the information specialist asks the patient to complete a questionnaire. The

questionnaire requests data that the expert system will need to tailor the Health Center for his needs.

After completing the questionnaire, the patient is free to visit any room of his choosing.

Elements of PIES

The Library

If the patient would like information, he is referred to the library. To get to the library, or any other room, the patient would click with the mouse on the door that leads to the desired area. The library is a highly-interactive area (see Figure 3) in which the patient may obtain, and interact with, educational material and other information. The library consists of a wall of shelves with many books to choose from. It also has a TV through which videos can be accessed. The books are sorted in alphabetical order; by "rolling over" a book with a mouse, its title is revealed. For example, a book entitled Brachytherapy (see Figure 4) contains information about radioactive-seed implant treatment.

A chapter gives an overview of brachytherapy; another chapter focuses on side effects, while another one describes the rationale behind a particular treatment regimen. Other books available contain information about psychosocial functioning, such as how to deal with impotence and incontinence, the use of alternative medicine, clinical trials, and the impact of prostate cancer on the family. The video section contains short videos (up to 5 minutes) that show facilities (eg, a surgical suite) and describe specific treatments. In sum, the library is a place that has a comprehensive collection of disease- and treatment-related materials that not only address the momentary concerns of the patient, but also assist in the preparation for future prostate-cancer and treatment-related consequences.

Figure 3. The PIES library

Sources of Information

The identification and development of the information contained in PIES is a multi-step process. A starting point for compiling information is a review of current information on prostate cancer treatment (eg, the PDQ [61]), that is approved by the National Cancer Institute [62] and the Cancer Information Service [63]. Regular Medline [64] searches supplement this information and ensure that it stays current. Second, the research team summarizes this information and identifies and develops appropriate visual materials. Third, medical expert consultants vet all materials for accuracy. Fourth, a health educator and a cancer-information specialist adopt the information to a 6th- to 7th-grade reading level. Last, information is then adopted for high and low information seekers.

Figure 4. Table of contents page for book on brachytherapy

Interacting with Physicians

The physician offices are on the second and third floor of the virtual health center. The physician offices are reached through an elevator, which contains a large sign that allows the user to click on the desired office. Experts in a treatment area (ie, surgeons, radiation oncologists, a physician specializing in brachytherapy) are available to provide information about different treatment modalities. After entering the office (see Figure 5), the patient interacts with the physician by selecting different video clips from a pull-down menu. Each video clip answers specific questions about the treatment, providing anatomical and technical information. In addition, physicians discuss issues such as who is a candidate for this treatment, the likelihood of side effects, success rates, recovery time, and expected quality of life.

Figure 5. Meeting with a physician
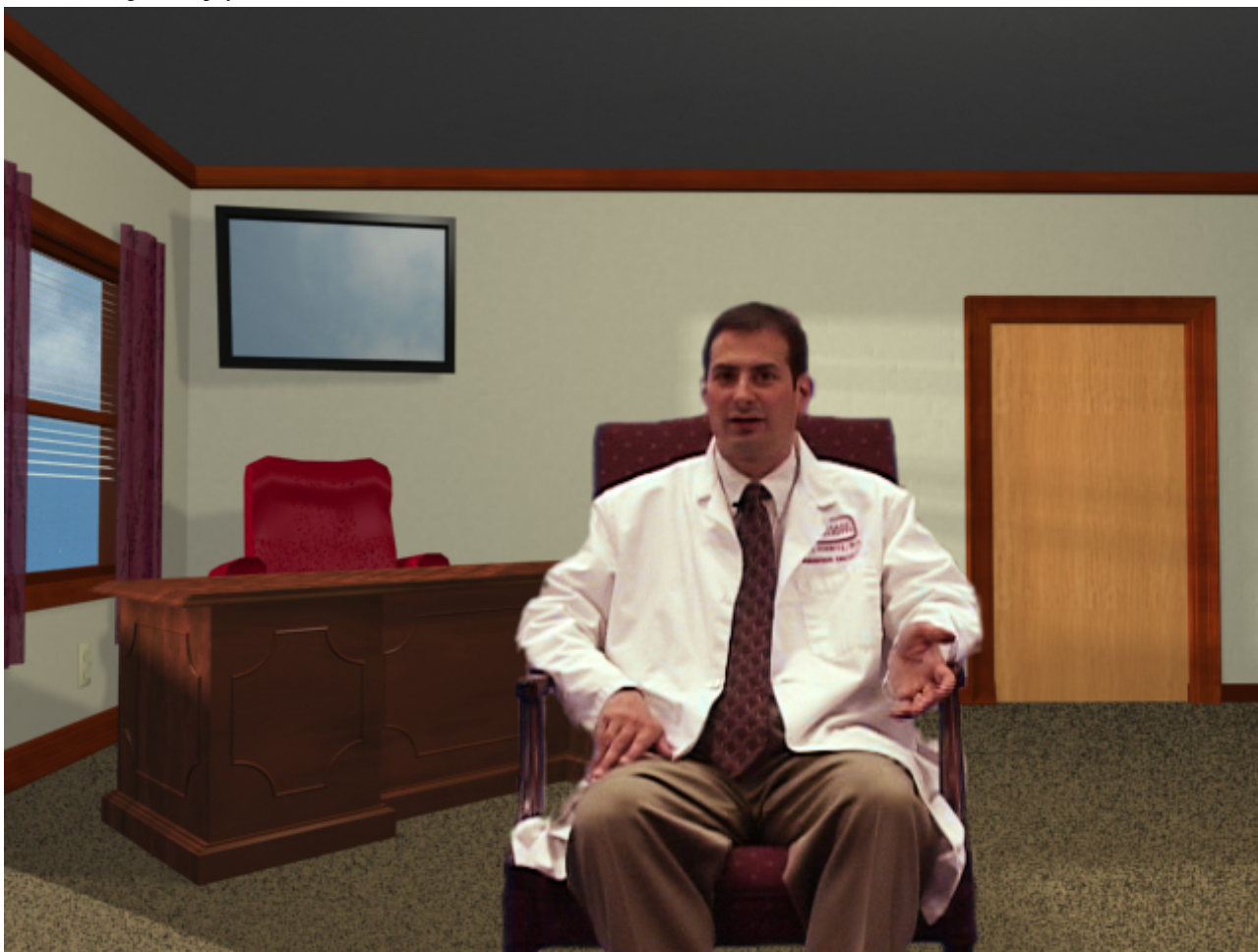
The Group Meeting Room

The patient may choose to participate in a group meeting of prostate cancer survivors. The members of these groups have experienced the range of treatment options. The patient may listen to the group members discuss with one another aspects of their treatment decision-making such as how they found out that they had prostate cancer, how they felt when they found they had the disease, and how they chose a treatment. Figure 6 shows members of the group discussing a wide-ranging array of topics that include sexual and incontinence problems, issues with intimacy, the effect of the disease on the partner, the influence of the spouse on treatment decision-making, experience with different treatments, and the use of alternative therapies.

Figure 6. Viewing a support-group session

The Notebook

If the participant wants to take notes or jot down a comment during his exploration of the Health Center, he can call up an electronic notebook, which is available from any room. The notebook will also be helpful to jot down notes when visiting the doctor-patient module. These notes might be helpful to the patient when he consults with physicians about prostate cancer. All notes will be incorporated in the final printed report that will be generated upon exiting the program.

Exiting the Software

When participants decide to exit, the software calculates which information had been accessed and offers information that has not been viewed to patients. For example, if a patient only inquired about surgical treatment for prostate cancer, the program offers information on external beam radiation and brachytherapy for reviewing. Thus, the software will ensure that all patients have had a balanced amount of information. If the patient desires, he can complete a decision aid, designed to elicit his values and goals with regard to prostate cancer treatment [65] and thus assist him in making a treatment decision that is right for him. After completing the decision aid, the software will also ask the patient if he wants to return to PIES. If the answer is yes, the expert system will update the patient's results folder before the program is closed. When a participant re-enters the software he is placed in the reception area to decide which part of the health center he wishes to visit. If the participant does not intend to revisit the software, it updates the results folder, and then generates a report for the patient. This report contains a synopsis of accessed information, notes that

were taken, areas the participant has not visited, and types of available information that he has not yet accessed.

Tailoring to Information Seeking Within PIES

Improved communication between physicians and patients and improved information provision about disease and its treatment are important factors in aiding patients to make treatment decisions and to cope with their disease [21,66,67]. Although, patients are generally interested in obtaining information about their disease, not all patients desire the same level of information [68,69] and thus an individualized approach to information provision is more appropriate to meet a patients information needs [70,71].

Research has identified 2 main profiles of information processing: high monitoring (information seeking) and low monitoring (information distracting). When confronted with medical information, high monitoring individuals typically process information very attentively and amplify its threatening aspects. High monitors prefer more information about their condition and its treatment, are consequently better informed, yet express greater dissatisfaction about the amount of information they receive [68]. Overall, they demand more support and reassurance [68,72].

In contrast, low monitors demonstrate an opposite pattern; they are more likely to ignore, avoid, and minimize threatening cancer-related information that diverges from their belief that they will be fine [41,73- 76]. Consequently, low monitors prefer and are satisfied with less information about their condition, are less knowledgeable about their disease status, and tend to underestimate the risk from the disease threat.

The expert system determines if the patient is a low monitor (ie, low information seeker), one who wants only the important points of a treatment, or a high monitor (ie, high information seeker), one who wants considerable detail about a treatment therapy. The expert system directs the interactive multimedia program to provide the amount of information that the patient desires. The expert system realizes that a patient might want to be a high monitor in some areas and a low monitor in others. For example, a patient may be very interested in knowing all about the side effects of external beam radiation while wanting only the essentials about the procedure itself. To our knowledge, PIES is unique in that it allows dynamic tailoring. Consequently, as patients proceed through PIES, its expert system determines how much information patients desire about a topic and provides it.

Survey to Establish Computer Literacy Among Target Audience

Before developing PIES we conducted a survey among the target audience (ie, men diagnosed with localized prostate cancer) to establish familiarity with computers. We mailed a brief questionnaire to 675 participants of an ongoing longitudinal study of prostate-cancer treatment decision making and quality of life [5].

Focus Groups to Evaluate PIES

We developed a demonstration CD of PIES to showcase its features to several focus groups. The first 3 focus groups consisted of 18 prostate cancer survivors. Men were recruited from the same ongoing longitudinal study mentioned above [5].

Results

Computer Literacy Among Target Audience

Of the 675 survey questionnaires mailed, 473 were returned (70% return rate). Demographic characteristics are listed in Table 1.

Table 1. Demographic characteristics of PIES users

Characteristic	Mean (SD)	Percentage of Sample
Age in Years	66 (8)	
35-45		0.2
46-55		10
56-65		34
66-75		47.8
> 75		8
Ethnicity		
Caucasian		92
African American		6
Hispanic		1
Asian/Pacific Islander		1
Education		
Completed grade school		7
Completed high school		47
Completed college		23
Post-graduate degree		23
Marital Status		
Married		85
Single/separated/widowed		15
Employment		
Retired		60
Full- and half-time employed		40

The majority (65%) of participants reported they have a PC at home, and an additional 7% indicated they had access to a PC at a public place, such as at work or at the library. Access to a computer came with access to the Internet for 70% of the respondents. When asked to rate their experience in using a computer, 80% of patients indicated they are familiar with computers. They rated their expertise from slightly experienced (39%), moderately experienced (18%), very experienced (11%), to expert (2%). Three quarters (76%) further indicated that they had access to a family member or a friend to help them with

potential computer problems. When asked about any physical problems that might prevent them from using a computer, 89% of patients reported not having any eye problems that might interfere with using a computer, and 83% indicated they have no difficulty at all in operating a pointing device such as a mouse (10% indicated having "a little problem" with a mouse). Patients who have a computer at home spend an average of 3 hours (SD = 1.5 hours) per week using it. About 20% spend more than 2 hours per day on the computer. Thus, our target audience for PIES is experienced in using a computer.

Of the 18 men, 7 (39%) were African American. We oversampled African American men into the focus groups, in part because, prostate cancer is particular prevalent among African Americans and thus the use of the program might be specifically relevant to this group. Men were on average 67 years old and had at least a high-school education (33%), a large majority was married (83%), and had completed treatment (83%). External beam radiation was chosen by 72%, 22% chose surgery, and 6% chose brachytherapy. The remaining 2 focus groups were held with spouses of prostate cancer survivors (N = 15). The women were on average 60 years old and 50% had a college or postgraduate degree. All focus group participants received $40 as a token of appreciation.

Focus Groups' Evaluation of PIES

Overall feedback on the demonstration CD was extremely positive. All ratings were performed on a 5-point scale, with higher scores indicating higher levels of interest. Patients and spouses uniformly stated that they were "very much" interested in the software (mean = 4.71; SD = 0.59; range, 3-5), and that it was "very" useful (mean = 4.71; SD = 0.47; range, 4-5). When asked whether they would prefer the software in lieu of traditional information sources, such as books or booklets, 83% stated a clear preference for the software program over print material, and 100% would prefer the program in addition to print material. On average, patients indicated that they would spend between 1 and 2 hours with the program and were willing to pay an average of $50 for it, if it were commercially available. A large majority of patients (82%) indicated that they had access to a personal computer and that they frequently use it (41% everyday, 29% 3-4 times a week, 18% 1-2 times a week); 94% had access to the Internet. In general, patients use their computer for e-mail (71%), and to obtain general (77%) and health (71%) information. Almost 60% have used the Internet to obtain prostate cancer information.

Concept of a Virtual Health Center With Rooms or Offices

Transcripts of the participants' comments revealed that participant's liked the concept of a virtual health center. Uniformly, the idea of going to rooms or offices to obtain information was found intuitive and appealing. Further, participants appreciated the variety of information that could be found in the program. The following summarizes comments by focus group members, organized by rooms.

Introduction

Men and spouses found the Introduction to PIES easy to follow and indicated that it gave an excellent overview of the program.

They particularly liked the possibility of accessing information in any order they liked and the program's capability of tailoring the information to their information-seeking needs. Participants also mentioned that they value an interface that mimics an interaction with a human. Some men suggested the inclusion of a guide who follows them around in the health center and who could be asked questions.

Physician's Office

The large majority of men and spouses (90% for each) indicated that they would visit the physician's offices first, before going to any other room. Participants liked the opportunity to type in a question, which will prompt the program to retrieve the appropriate video with the physician answering the questions. However, a majority of patients also requested an overview of available physician answers. As one man stated: "After a diagnosis I didn't know what type of questions to ask. An index of available information from the physician would be very helpful." Some men also didn't like the physician sitting behind a desk, which increased the perceived distance between patient and physician. The current version of PIES places the physician in a comfortable chair in front of the desk.

Library

Participants loved the layout of the library and found the idea of providing information in book form very appealing. They particularly appreciated the combination of written text with illustrations and short video clips. Some men voiced interest in watching video clips of surgical or seed-implantation procedures. Others, in contrast, indicated that they would not be interested in such a level of detail, providing unwitting support for our plans to tailor information to their monitoring preference. Both patients and spouses liked that some medical terms were hyperlinked to the Glossary, which provided short one-sentence explanations of the term.

Support Group

In general, men showed great interest in watching video clips of prostate cancer survivors sharing their experience. In the initial format there were 3 men sitting behind a table answering questions that were keyed in by the patient. While about half of the patients appreciated the opportunity to interact with each man directly in the support group, the other half was interested in watching the men exchanging their ideas. The current version of the software includes videotapes of men discussing certain topics, such as treatment decision-making, treatment experience, and post-treatment quality of life.

Topics Specifically Mentioned in Focus Groups With Spouses

Certain topics were specifically mentioned in the focus groups with spouses. Spouses advocated for a room that provided information specific to their information needs. Topics of interest were information about nutrition (eg, soy, lycopenes), emotional support (both resources for support, as well as learning from the experience of other spouses), as well as instrumental support, particularly with caregiving after treatment. Spouses were also interested to receive information about sexual issues as it pertains to intimacy, communicating

to one's spouse about sexual issues, and the use of devices to assist a patient with erectile dysfunction.

Summary

In summary, both men and spouses were enthusiastic about the program. They expressed great interest and regretted not having had such a tool when they had to make a treatment decision. When given the choice between traditional information sources such as books or pamphlets almost every participant indicated a preference for the CD-ROM. Of particular interest to patients were the physician's office and the support-group room, which offered patients expert as well as lay perspectives of prostate cancer treatments. Although men expressed proficiency with computers in general, it became clear that additional navigational and organizational help would enhance the usability of PIES.

Discussion

In this paper we have introduced the development and preliminary evaluation of novel multimedia-education software for prostate cancer patients. The article started with a brief review of the major developments in computer-aided learning, particularly emphasizing research and development efforts in the area of providing (tailored and nontailored) health information and education. We then introduced the PIES architecture, described the visual interface, content development, and preliminary evaluation through focus groups.

Plans for a Virtual Information Specialist and Interactive Tutor (VISIT)

Overall, the focus group members evaluated PIES very positively and provided important suggestions about potential changes and enhancements to the program. Based on these comments and in accordance with health-behavior and communication theories [7,77] we are planning to enhance the next version of the PIES software by including a virtual information specialist and interactive tutor (VISIT). This information specialist and tutor will be designed to further enhance the interactivity between user and software. Specifically, VISIT will proactively query the user about what kind of information he desires, inform him where he can obtain the information, and will offer to retrieve it for him. VISIT will further guide the user through the program by offering relevant information that had not been accessed, thus anticipating the user's informational needs. Furthermore, while offering treatment information that could be upsetting to some patients the program will also offer emotionally-reassuring and normalizing messages.

VISIT will be represented as a health care professional (see Figure 7) through video and still photos. Once the patient enters the health center, she will introduce herself and will give an overview of the center. She will offer suggestions on how to best use the program, depending on the user's needs. For example, if a patient is interested in hearing a physician's opinion, VISIT will offer to show him the way to the doctor's office. In contrast, if the patient is interested in learning about different treatment modalities in great detail, VISIT will accompany him into the library. Once there, VISIT will query the user about which treatment options he might want to learn about first and which aspects he is most interested. The corresponding information will then be presented.

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Figure 7. The virtual information specialist and interactive tutor (VISIT) at her desk
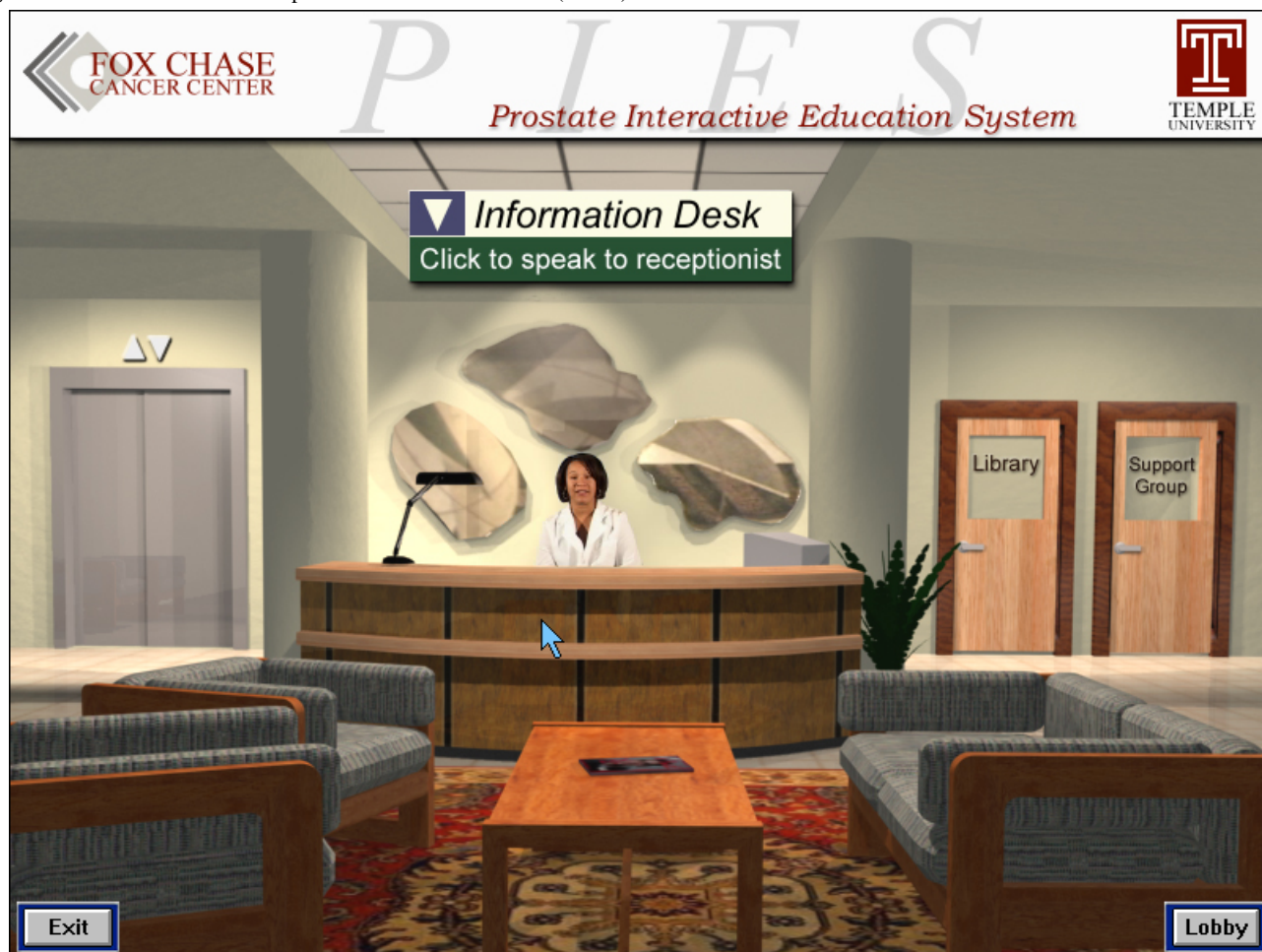
Areas in Which VISIT Will Increase the Functionality of PIES

Provide Balanced Picture of Treatment Options

Most importantly, VISIT will ensure that the patient receives a balanced picture of all treatment options. Patients who are accessing information about only one treatment option will be queried by VISIT as to whether they are interested in receiving relevant information about other treatment modalities. VISIT will present the information or offer to take the patient to the appropriate room.

Increase Retention of Information and Provide Emotional Reassurance

VISIT is designed to increase the patient's retention of the presented information and to provide emotionally-reassuring and normalizing messages. In particular, after a module is completed VISIT will summarize the information that was given to the patient. In this context, VISIT will emphasize that prostate cancer is a common disease among men, that the tumor is slow growing and highly treatable. Furthermore, VISIT will offer information about support groups and additional information on the Internet.

Raise Patient's Perceived Self-Efficacy

Another area that will be addressed through VISIT is to raise the patient's perceived self-efficacy to deal with his condition.

On the one hand, this will be achieved by providing information that is tailored to the patient's information-seeking needs. On the other hand, VISIT will provide concrete suggestions designed to enhance the patient's communication skills with his provider. VISIT will display sample interactions between patient and physician.

Short video clips depicting situations in which the patient is successful in requesting and obtaining information about his treatment options from the physician will represent these interactions. After watching these short video clips, VISIT will summarize the most important communication practices, including sample questions, that the patient can use to enhance his communication with his provider.

Suggest Completion of a Treatment Decision Aid

Finally, after the user has accessed a sufficient amount of information, VISIT will suggest the completion of a treatment decision aid. Completing a decision aid will be a 2-step process and follows the latest findings in theory and research [36].

In Step 1 the patient is asked to identify and rank his treatment-related values and goals. Specifically, he is asked to complete a table that will allow him to list attributes that are important for him (such as high rate of success, convenience, avoidance of pain). The patient can choose from a list of commonly-named treatment-related attributes as well as include

and rank his own goals. When completed this table will consist of his own list ranked by importance of treatment-related goals.

In Step 2 the computer will carry over the ranked items into a larger table that consists of rows and columns. In column 1 the ranked items appear; the columns to the right represent the different treatment choices (eg, surgery, brachytherapy). Now the patient is asked to rate how well, in his mind, each treatment addresses his ranked attributes. Ratings will be done on a 5-point scale (1 = not at all, 5 = completely). If the patient feels that he has not enough information he can enter a question mark. This will serve as a reminder to either query PIES for further information on this issue or discuss this issue with his physician. The computer will automatically tally up the ratings and will summarize the results for him. A sample paragraph could read like this:

```
According to your ratings, it is very important
to you to not experience urinary problems
and to be able to maintain an active lifestyle.
You also mentioned that you favor a high
likelihood to cure the cancer, and are quite a bit
 worried about pain and recovery time.
Your ratings suggest that you are leaning towards
 radiation therapy, specifically
external radiation therapy. To learn more about
this therapy please click here. You might
also want to talk to a radiation oncologist about
 this treatment option.
```

After the user completes the decision aid, VISIT will ask whether the user would like to print any of the patient's notes before exiting the program.

Limitations

Our preliminary evaluation has some limitations. First, focus group members evaluated a demonstration CD, designed to elicit input about the metaphor, its presentation, and possible content. These individuals had successfully completed treatment and thus their information needs were not as immediate as those

of just-diagnosed patients. Yet, a number of survivors and spouses mentioned that they wished they had PIES while they were learning about prostate cancer. It should also be pointed out that PIES is intended to serve as an additional patient-education tool. It is not designed to substitute for personal consultations with a physician. Indeed numerous statements will be made to encourage the patient to discuss specific individual medical issues with a health care provider.

Next Step

The next step in the evaluation of PIES will involve extensive usability testing with a patient sample. We will use the methodology and procedures set forth by the National Cancer Institute's own usability program (Usability.gov, [78]). Patients will be asked to talk aloud while exploring an alpha version of PIES, detailing what type of information they are looking for, where they think they can find it, and their reactions to it. Based on current usability standards we estimate that a small number of users (ie, approximately 5 patients) is sufficient to detect the majority of bugs. All suggestions from the usability version will be incorporated into a beta version of the program. This version will then be evaluated for efficacy in a randomized controlled trial, in which PIES will be evaluated against standard care (ie, information provided through brochures and pamphlets).

Conclusions

In this paper we have introduced a novel interactive multimedia system for prostate cancer education and treatment decision making. PIES is based on current psychological theory incorporating tailoring to information-seeking preferences with the latest software technology. The program is highly interactive, combining user input with animation, video, text, and still photos. Preliminary evaluation through focus groups has established the validity of our approach and has pointed to new directions to further enhance the user interface through the development of a virtual information specialist and interactive tutor.

Conflicts of Interest

None declared.

Multimedia Appendix

Screenshots of PIES (Prostate Interactive Education System): [PPT File, 3.3MB - jmir_v6i1e3_app1.ppt]

References

1. ; American Cancer Society. Cancer facts & figures 2003. 2003. URL: http://www.cancer.org/downloads/STT/CAFF2003PWSecured.pdf [accessed 2004 Jan 14]
2. Millikan R, Logothetis C. Update of the NCCN guidelines for treatment of prostate cancer. Oncology (Huntingt) 1997 Nov;11(11A):180-193. [Medline: 98092024]
3. Baker LH, Hanks G, Gershenson D, Kantoff P, Lange P, Logothetis C, et al. NCCN Prostate Cancer Practice Guidelines. The National Comprehensive Cancer Network. Oncology (Huntingt) 1996 Nov;10(11 Suppl):265-288. [Medline: 97111840]

4. Barry MJ, Fowler FJ, Mulley AG, Henderson JV, Wennberg JE. Patient reactions to a program designed to facilitate patient participation in treatment decisions for benign prostatic hyperplasia. Med Care 1995 Aug;33(8):771-782. [Medline: 95364425]

5. Diefenbach MA, Dorsey J, Uzzo RG, Hanks GE, Greenberg RE, Horwitz E, et al. Decision-making strategies for patients with localized prostate cancer. Semin Urol Oncol 2002 Feb;20(1):55-62. [Medline: 21686548] [doi: 10.1053/suro.2002.30399]

6. Butz BP. Expert systems. Abacus 1987;5(1):30-44.

7. Miller SM, Diefenbach MA. The cognitive-social health information processing (C-SHIP) model: a theoretical framework for research in behavioral oncology. In: Krantz D, editor. Perspectives in Behavioral Medicine. Mahwah, NJ: Lawrence Erlbaum; 1998:219-244.

8. Buchanan BG. In: Shortliffe EH, editor. Rule Based Expert Systems: The Mycin Experiments of the Stanford Heuristic Programming Project (The Addison-Wesley series in artificial intelligence). Reading, MA: Addison-Wesley; Jun 1, 1984.

9. Anderson JR, Boyle CF, Resier BJ. Intelligent tutoring systems. Science 1985;228:456-462.

10. Skinner CS, Strecher VJ, Hospers H. Physicians' recommendations for mammography: do tailored messages make a difference? Am J Public Health 1994 Jan;84(1):43-49. [Medline: 94106682]

11. Brown JS, Burton RR. Diagnostic models for procedural bugs in basic mathematical skills. Cognitive Science 1978;2(2):155-192. [doi: 10.1016/S0364-0213(78)80004-4]

12. Wenger E. Artificial Intelligence and Tutoring Systems: Computational and Cognitive Approaches to the Communication of Knowledge. Los Altos, CA: Morgan Kaufmann Pub; Oct 1, 1987.

13. Polson M, Richardson JJ, editors. Foundations of Intelligent Tutoring Systems. New York, NY: Lea; May 1, 1988.

14. Van Lehn K. Conceptual and metalearning during coached problem solving. In: Frasson C, Gauthier G, Lesgold A, editors. Intelligent Tutoring Systems: Third International Conference, Its '96: Proceedings (Lecture Notes in Computer Science). New York: Springer; Jun 1, 1996.

15. Sears AL, Watkins SE. A multimedia manual on the World Wide Web for telecommunications equipment. IEEE Transactions on Education 1996;39(3):342-348. [doi: 10.1109/13.538757]

16. Butz BP. Interactive multimedia software for a course in introductory circuits. Presented at: AACE World Conference on Educational Multimedia and Hypermedia; 1997; Calgary, Alberta, Canada.

17. Edminister JA, Nahvi M. Schaum's Outline of Electric Circuits. New York: McGraw-Hill Trade; May 1, 1995.

18. Mosterman PJ, Campbell JO, Brodersen AJ, Bourne JR. Design and implementation of an electronics laboratory simulator. IEEE Transactions on Education 1996;39(3):309-313. [doi: 10.1109/13.538752]

19. Bergland M, Klyczek K, Lundeberg M, Mogen K, Johnson D. Case It! A project to integrate collaborative case-based learning into international undergraduate biology curricula. Presented at: 10th International Conference on College Teaching and Learning; 1999; Jacksonville, FL.

20. Harger RO. Teaching in a computer classroom with a hyperlinked, interactive book. IEEE Transactions on Education 1996;39(3):327-335. [doi: 10.1109/13.538755]

21. Butz BP. Freedom of choice in an intelligent tutoring system. Presented at: 1999 Meeting of the American Society for Engineering Education; 1999; Charlotte, NC.

22. Butz BP. An interactive multimedia intelligent tutoring system. Presented at: 10th International Conference on College Teaching and Learning; 1999; Jacksonville, FL.

23. Sleeman D, Brown JS, editors. Intelligent Tutoring Systems (Computers and People Series). New York, NY: Academic Press; 1997.

24. Lewis M. Designing for human-agent interaction. AI Magazine 1998;19(2):67-78.

25. Milton-Benoit J, Grosse IR, Poli C, Woolf BP. The multimedia finite element modeling and analysis tutor. ASEE Journal of Engineering Education 1998;87(5):511-518.

26. Hofstetter FT. Multimedia Literacy with Student CD-ROM. New York, NY: Irwin/McGraw-Hill; Oct 3, 2000.

27. Shortliffe EH, Buchanan BG. A model of inexact reasoning in medicine. Mathematical Biosciences 1975;23(3-4):351-379. [doi: 10.1016/0025-5564(75)90047-4]

28. Pople HE, Myers JD, Miller RA. DIALOG: a model of diagnostic logic for internal medicine. In: Proceedings of the Fourth International Joint Conference on Artificial Intelligence. Tiblisi, Georgia: Morgan Kaufman; 1975:848-855.

29. Chandrasekaran B, Gomez F, Mittal S, Smith J. An approach to medical diagnosis based on conceptual structures. In: Proceedings of the Sixth International Joint Conference on Artificial Intelligence. Tokyo, Japan. San Francisco, CA: Morgan Kaufman; 1979:134-142.

30. Gorry GA, Silverman H, Pauker SG. Capturing clinical expertise. A computer program that considers clinical responses to digitalis. Am J Med 1978 Mar;64(3):452-460. [Medline: 78142148] [doi: 10.1016/0002-9343(78)90232-2]

31. Flynn G. Medicine in the age of the computer. Englewood Cliffs, NJ: Prentice-Hall; 1996.

32. Quaglini S, Barahona P, Andreassen S. Proceedings of the 8th Conference on AI in Medicine in Europe. Cascais, Portugal: Springer; Jul 1, 2001.

33. Binnie C, Spreng M. The epilepsy tutorial. Stud Health Technol Inform 2000;78:213-284. [Medline: 21026107]

34.   Michel MS, Knoll T, Köhrmann KU, Alken P. The URO Mentor: development and evaluation of a new computer-based interactive training system for virtual life-like simulation of diagnostic and therapeutic endourological procedures. BJU Int 2002 Feb;89(3):174-177. [Medline: 21845389] [doi: 10.1046/j.1464-4096.2001.01644.x]

35.   Müller-wittig WK, Bisler A, Bockholt U, Los Arcos JL, Oppelt P, Stähler J, et al. LAHYSTOTRAIN development and evaluation of a complex training system for hysteroscopy. Stud Health Technol Inform 2001;81:336-340. [Medline: 21216060]

36.   Zaharakis ID, Kameas AD, Nikiforidis GC. A multi-agent architecture for teaching dermatology. Med Inform (Lond) ;23(4):289-307. [Medline: 99121705]

37.   Ambrosiadou BV, Ketikidis PH. DIABETOR computer aided tutoring in diabetes management. Stud Health Technol Inform 1997;43 Pt B:694-698. [Medline: 98262160]

38.   Johnson KA, Smith JW, Dejongh M, Fischer O, Amra NK, Bayazitoglu A. RedSoar--a system for red blood cell antibody identification. Proc Annu Symp Comput Appl Med Care 1991:664-668. [Medline: 92223821]

39.   Tambe M, Johnson WL, Jones RM, Koss F, Laird JE, Rosenbloom PS, et al. Intelligent agents for interactive simulation environments. AI Magazine 1995;16(1):15-39.

40.   Binik YM, Servan-schreiber D, Freiwald S, Hall KS. Intelligent computer-based assessment and psychotherapy. An expert system for sexual dysfunction. J Nerv Ment Dis 1988 Jul;176(7):387-400. [Medline: 88316248]

41.   Agre P, Dougherty J, Pirone J. Creating a CD-ROM program for cancer-related patient education. Oncol Nurs Forum 2002 Apr;29(3):573-580. [doi: 10.1188/02.ONF.573-580] [Medline: 21975669]

42.   Guendelman S, Meade K, Benson M, Chen YQ, Samuels S. Improving asthma outcomes and self-management behaviors of inner-city children: a randomized trial of the Health Buddy interactive device and an asthma diary. Arch Pediatr Adolesc Med 2002 Feb;156(2):114-120. [Medline: 21673311]

43.   Dragone MA, Bush PJ, Jones JK, Bearison DJ, Kamani S. Development and evaluation of an interactive CD-ROM for children with leukemia and their families. Patient Educ Couns 2002 Apr;46(4):297-307. [Medline: 21930585] [doi: 10.1016/S0738-3991(01)00166-5]

44.   Valdez A, Banerjee K, Fernandez M, Ackerson L. Impact of a multimedia breast cancer education intervention on use of mammography by low-income Latinas. J Cancer Educ 2001;16(4):221-224. [Medline: 21837205]

45.   Neafsey PJ, Strickler Z, Shellman J, Padula AT. Delivering health information about self-medication to older adults: use of touchscreen-equipped notebook computers. J Gerontol Nurs 2001 Nov;27(11):19-27. [Medline: 21678078]

46.   Shaw MJ, Beebe TJ, Tomshine PA, Adlis SA, Cass OW. A randomized, controlled trial of interactive, multimedia software for patient colonoscopy education. J Clin Gastroenterol 2001 Feb;32(2):142-147. [Medline: 21075110] [doi: 10.1097/00004836-200102000-00010]

47.   Wardle J, Steptoe A, Smith H, Groll-knapp E, Koller M, Brodziak A. Breast self-examination: attitudes and practices among young women in Europe. Eur J Cancer Prev 1995 Feb;4(1):61-68. [Medline: 95245276]

48.   Berridge E, Roudsari A, Taylor S, Carey S. Computer-aided learning for the education of patients and family practice professionals in the personal care of diabetes. Comput Methods Programs Biomed 2000 Jul;62(3):191-204. [Medline: 20298610] [doi: 10.1016/S0169-2607(00)00067-5]

49.   Hornung RL, Lennon PA, Garrett JM, Devellis RF, Weinberg PD, Strecher VJ. Interactive computer technology for skin cancer prevention targeting children. Am J Prev Med 2000 Jan;18(1):69-76. [Medline: 20266982] [doi: 10.1016/S0749-3797(99)00115-4]

50.   Block G, Miller M, Harnack L, Kayman S, Mandel S, Cristofar S. An interactive CD-ROM for nutrition screening and counseling. Am J Public Health 2000 May;90(5):781-785. [Medline: 20260224]

51.   Consoli SM, Ben Said M, Jean J, Menard J, Plouin PF, Chatellier G. Benefits of a computer-assisted education program for hypertensive patients compared with standard education tools. Patient Educ Couns 1995 Sep;26(1-3):343-347. [Medline: 96037507] [doi: 10.1016/0738-3991(95)00747-N]

52.   Gustafson DH, Bosworth K, Hawkins RP, Boberg EW, Bricker E. CHESS: a computer-based system for providing information, referrals, decision support and social support to people facing medical and other health-related crises. Proc Annu Symp Comput Appl Med Care 1992:161-165. [Medline: 93129896]

53.   Gustafson DH, Hawkins R, Boberg E, Pingree S, Serlin RE, Graziano F, et al. Impact of a patient-centered, computer-based health information/support system. Am J Prev Med 1999 Jan;16(1):1-9. [Medline: 99111919] [doi: 10.1016/S0749-3797(98)00108-1]

54.   Mctavish FM, Gustafson DH, Owens BH, Wise M, Taylor JO, Apantaku FM, et al. CHESS: An interactive computer system for women with breast cancer piloted with an under-served population. Proc Annu Symp Comput Appl Med Care 1994:599-603. [Medline: 95037318]

55.   Kreuter MW, Strecher VJ, Glassman B. One size does not fit all: the case for tailoring print materials. Ann Behav Med 1999;21(4):276-283. [Medline: 20186211]

56.   Cook TD, Flay BR. The temporal persistence of experimentally induced attitude change: an evaluative review. In: Berkowitz L, editor. Advances in Experimental Social Psychology. New York: Academic Press; 1978, Vol. 11.

57.   Butow PN, Dunn SM, Tattersall MH, Jones QJ. Patient participation in the cancer consultation: evaluation of a question prompt sheet. Ann Oncol 1994 Mar;5(3):199-204. [Medline: 94242685]

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58. Petty RE. The importance of cognitive responses in persuasion. Advances in Consumer Research 1977;4:357-362.

59. Skinner CS, Campbell MK, Rimer BK, Curry S, Prochaska JO. How effective is tailored print communication? Ann Behav Med 1999;21(4):290-298. [Medline: 20186213]

60. ; Macromedia Inc. Authorware [computer program]. URL: http://www.macromedia.com/ [accessed 2004 Jan 14]

61. ; National Cancer Institute. About PDQ. URL: http://www.cancer.gov/cancerinfo/pdq/treatment/prostate/patient/#Section_AboutPDQ_14 [accessed 2004 Jan 14]

62. ; National Cancer Institute. Home page. URL: http://www.cancer.gov/ [accessed 2004 Jan 14]

63. ; National Cancer Institute. Cancer Information Service. URL: http://cis.nci.nih.gov/ [accessed 2004 Jan 14]

64. ; National Library of Medicine. Medline. URL: http://www.ncbi.nlm.nih.gov/PubMed/ [accessed 2004 Jan 14]

65. O'connor AM, Rostom A, Fiset V, Tetroe J, Entwistle V, Llewellyn-thomas H, et al. Decision aids for patients facing health treatment or screening decisions: systematic review. BMJ 1999 Sep 18;319(7212):731-734 [FREE Full text] [PMC: 10487995] [Medline: 99418906]

66. Brandt B. Informational needs and selected variables in patients receiving brachytherapy. Oncol Nurs Forum 1991 Sep-Oct;18(7):1221-1227 discussion 1227-1229. [Medline: 194596]

67. Ford S, Fallowfield L, Hall A, Lewis S. The influence of audiotapes on patient participation in the cancer consultation. Eur J Cancer 1995 Dec;31A(13-14):2264-2269. [Medline: 96262864] [doi: 10.1016/0959-8049(95)00336-3]

68. Miller SM. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. Cancer 1995 Jul 15;76(2):167-177. [Medline: 96223011]

69. Leydon GM, Boulton M, Moynihan C, Jones A, Mossman J, Boudioni M, et al. Faith, hope, and charity: an in-depth interview study of cancer patients' information needs and information-seeking behavior. West J Med 2000 Jul;173(1):26-31 [FREE Full text] [Medline: 0010903285] [doi: 10.1136/ewjm.173.1.26]

70. Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? J Clin Epidemiol 1992 Sep;45(9):941-950. [Medline: 93057674] [doi: 10.1016/0895-4356(92)90110-9]

71. Forrow L, Wartman SA, Brock DW. Science, ethics, and the making of clinical decisions. Implications for risk factor intervention. JAMA 1988 Jun 3;259(21):3161-3167. [Medline: 88215156] [doi: 10.1001/jama.259.21.3161]

72. Ong LM, Visser MR, Van Zuuren FJ, Rietbroek RC, Lammes FB, De Haes JC. Cancer patients' coping styles and doctor-patient communication. Psychooncology 1999;8(2):155-166. [Medline: 99268040]

73. Miller SM, Mangan CE. Interacting effects of information and coping style in adapting to gynecologic stress: should the doctor tell all? J Pers Soc Psychol 1983 Jul;45(1):223-236. [Medline: 83294013] [doi: 10.1037//0022-3514.45.1.223]

74. Miller SM, Roussi P, Altman D, Helm W, Steinberg A. Effects of coping style on psychological reactions of low-income, minority women to colposcopy. J Reprod Med 1994 Sep;39(9):711-718 [FREE Full text] [Medline: 95106224]

75. Miller SM, Shoda Y, Hurley K. Applying cognitive-social theory to health-protective behavior: breast self-examination in cancer screening. Psychol Bull 1996 Jan;119(1):70-94. [Medline: 96137761] [doi: 10.1037//0033-2909.119.1.70]

76. Tercyak KP, Lerman C, Peshkin BN, Hughes C, Main D, Isaacs C, et al. Effects of coping style and BRCA1 and BRCA2 test results on anxiety among women participating in genetic counseling and testing for breast and ovarian cancer risk. Health Psychol 2001 May;20(3):217-222. [Medline: 21295843] [doi: 10.1037//0278-6133.20.3.217]

77. Rostom A, O'connor A, Tugwell P, Wells G. A randomized trial of a computerized versus an audio-booklet decision aid for women considering post-menopausal hormone replacement therapy. Patient Educ Couns 2002 Jan;46(1):67-74. [Medline: 21664336] [doi: 10.1016/S0738-3991(01)00167-7]

78. ; National Cancer Institute. Usability.gov. URL: http://www.usability.gov/ [accessed 2004 Jan 14]

Abbreviations

PIES: prostate interactive education system
VISIT: virtual information specialist and interactive tutor

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<u>Original Paper</u>

Pharmacist Computer Skills and Needs Assessment Survey

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Abstract

Background: To use technology effectively for the advancement of patient care, pharmacists must possess a variety of computer skills. We recently introduced a novel applied informatics program in this Canadian hospital clinical service unit to enhance the informatics skills of our members.

Objective: This study was conducted to gain a better understanding of the baseline computer skills and needs of our hospital pharmacists immediately prior to the implementation of an applied informatics program.

Methods: In May 2001, an 84-question written survey was distributed by mail to 106 practicing hospital pharmacists in our multi-site, 1500-bed, acute-adult-tertiary care Canadian teaching hospital in Vancouver, British Columbia.

Results: Fifty-eight surveys (55% of total) were returned within the two-week study period. The survey responses reflected the opinions of licensed BSc and PharmD hospital pharmacists with a broad range of pharmacy practice experience. Most respondents had home access to personal computers, and regularly used computers in the work environment for drug distribution, information management, and communication purposes. Few respondents reported experience with handheld computers. Software use experience varied according to application. Although patient-care information software and e-mail were commonly used, experience with spreadsheet, statistical, and presentation software was negligible. The respondents were familiar with Internet search engines, and these were reported to be the most common method of seeking clinical information online. Although many respondents rated themselves as being generally computer literate and not particularly anxious about using computers, the majority believed they required more training to reach their desired level of computer literacy. Lack of familiarity with computer-related terms was prevalent. Self-reported basic computer skill was typically at a moderate level, and varied depending on the task. Specifically, respondents rated their ability to manipulate files, use software help features, and install software as low, but rated their ability to access and navigate the Internet as high. Respondents were generally aware of what online resources were available to them and Clinical Pharmacology was the most commonly employed reference. In terms of anticipated needs, most pharmacists believed they needed to upgrade their computer skills. Medical database and Internet searching skills were identified as those in greatest need of improvement.

Conclusions: Most pharmacists believed they needed to upgrade their computer skills. Medical database and Internet searching skills were identified as those in greatest need of improvement for the purposes of improving practice effectiveness.

Introduction

Pharmacy is an information intensive profession. The availability of affordable computers and the advancement of information technology have resulted in our ability to rapidly and effectively access, retrieve, analyze, share, and store large volumes of information pertinent to patient care [1].

To use technology effectively for the advancement of patient care, pharmacists must possess a variety of computer skills. We recently introduced a novel program in our clinical service unit at this hospital, aimed at the improvement of the applied informatics abilities of our members. In keeping with the broad mandate to introduce this program, this study was conducted to gain a better understanding of the computer skills and needs of our pharmacists.

Methods

This study involved a survey of all practicing licensed pharmacists at Vancouver Hospital and Health Sciences Centre, a multi-site, 1500-bed, acute-adult-tertiary care Canadian teaching hospital in Vancouver, British Columbia. This survey was conducted in May 2001.

Subjects

The participants of this study were licensed BSc and PharmD pharmacists at two of our hospital sites (Vancouver General Hospital, University of British Columbia Hospital). A computerized drug distribution system has been in use at both hospitals for at least 10 years.

Survey Instrument

To assess the computer skill sets of the participants, an 84-question written survey was created (Appendix 1). A review of the literature was undertaken to identify previously published surveys [2,4- 8]. None of these published instruments met all our needs. Some knowledge and experiential domains were adopted from this previous literature, and questions that were applicable to our purposes were either adopted or modified for inclusion in our survey. The majority of questions were developed internally by author consensus. Our survey was constructed to elicit information in nine primary domains relevant to identifying training needs and system barriers to the expanded use of technology in clinical practice. These domains were: 1) computer experience; 2) computer anxiety; 3) computer vocabulary; 4) basic computer skills; 5) communications; 6) Internet skills; 7) clinical database information retrieval; 8) access to computers; 9) anticipated future needs. Five-point scales were employed where self-assessment questions were posed. Clinical database and search-engine questions were limited to the hardware, software, and online resources that were currently available to our members.

The survey was distributed to the mailboxes of 106 casual, part-time, and full-time staff pharmacists at the two hospital sites. A covering letter was attached explaining the rationale for the survey and the anonymity of results, and requesting return of the survey within two weeks.

Data Analysis

Survey data were entered into a relational database (SPSS 10.1) [3] for the purposes of analysis. Incomplete surveys were included in the analysis and proportional data were expressed in terms of the number of respondents who answered a particular question. Descriptive analysis was also undertaken with the support of this software.

Results

Of the 106 surveys distributed to the pharmacists, 58 surveys (55% of total) were returned within the two-week study period.

Demographics

Surveys were completed by 58 pharmacists, including 20 (35%) residency-trained BSc (Pharm) pharmacists, 18 (31%) non-residency-trained pharmacists, 9 (16%) advanced degree (PharmD) pharmacists, 6 (10%) pharmacy supervisors, and 2 (3%) others. Pharmacist classification was undeclared for 3 (5%) respondents.

Twenty-six (45%) respondents had been in pharmacy practice for a period of 5 years or less. Eighteen (31%) respondents had been in practice for 6 to15 years, and 12 (21%) had been in practice for more than 15 years. Two (3%) respondents did not state duration of practice.

Computer Experience

General

Forty-five (79%) of 57 respondents had received no formal computer training. Fifty-two respondents (93%) owned a home computer. Thirty (52%) respondents used their home computers as much as 5 hours per week, and 23 (40%) respondents used their computers 6 to 15 hours per week. Only 12 (21%) respondents had completed some formal computer training.

Of those who provided a response, 27 (47%) respondents used work computers as much as 5 hours per week for activities other than drug distribution purposes, and a remaining 28 (48%) respondents used work computers 6 to15 hours per week for activities other than drug distribution purposes.

Thirty-nine (67%) respondents had never used a handheld computer at work or at home (e.g. a Palm-based device), but 16 (28%) used this type of device daily.

Software

Pharmacists were asked to state how frequently they used six general types of software packages. Of those who provided a response, 47 (81%) used e-mail software at least once daily, and 20 (35%) used word processing software daily. The vast majority (>90%) of respondents did not use any statistical analysis or presentation software.

Forty-two (72%) respondents used the patient-care information computer for prescription processing on a daily basis. Forty-nine (85%) respondents used this computer system to review laboratory test results on a daily basis.

Figure 1 shows the frequency of use, according to respondent, of three types of search engines (i.e. an Internet search engine such as Google, or the specific medical database search engines Ovid or PubMed) for the purpose of finding clinical information. Thirty-nine (67%) respondents used one or more of the search engines at least on a weekly basis. A general Internet search engine such as Google was the most commonly used vehicle for finding clinical information according to 36 of 58 respondents (62%), followed by Ovid (30, 51%), and PubMed (26, 45%).

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Figure 1. Frequency of search engine use by respondents (N= 58)
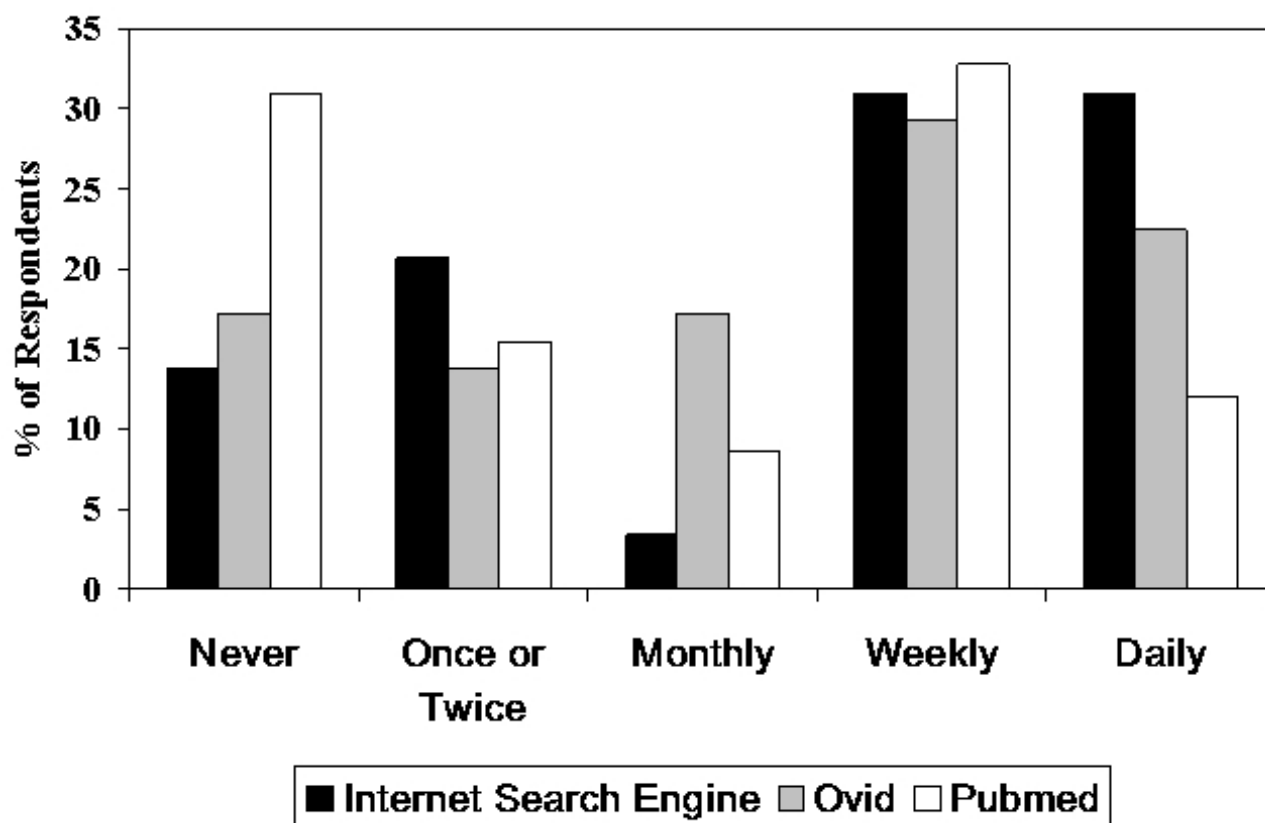
Computer Literacy and Anxiety

Using 5-point scales, pharmacists were asked to rate their current computer literacy and to compare this to their desired level of literacy (Figure 2, Figure 3). Respondents most commonly (24, 41%) ranked themselves as a "3" on the 5-point computer literacy scale. The majority (32, 55%) felt they needed more training to improve their computer literacy.

Pharmacists were asked whether or not the use of computers for purposes other than prescription processing or reviewing patient care information was anxiety provoking. Thirty-five (61%) respondents stated it was not; the remaining respondents stated that computer use caused varying degrees of anxiety (Figure 4).

Computer Vocabulary

Pharmacists were asked to indicate their ability to define ten computer- and software-related terms. Although there appeared to be an understanding of most terms, 35 (61%) respondents were unable to describe a local area network (LAN), 26 (46%) were unfamiliar with PDF documents, 25 (44%) could not describe network drives, and 23 (40%) were unfamiliar with the term "URL address."

Basic Computer Skills

Using a 5-point scale, pharmacists were asked to rate their ability to perform a variety of basic computer skills. The majority of respondents (42, 74%) rated their overall file management skills as "3" or greater. Twenty (35%) respondents stated that the specific computer task posing the greatest difficulty was file manipulation (e.g. copying and pasting a file or folder), 21 (37%) stated it was using software help features, and 25 (44%) stated it was installing software.
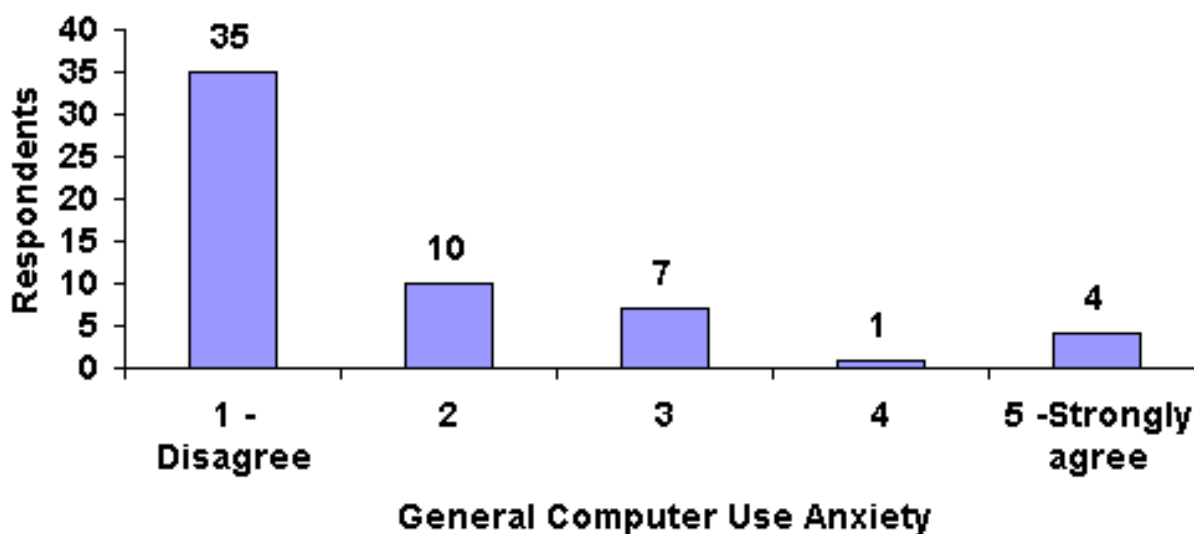
Figure 2. Computer literacy rating by respondents (N=58)
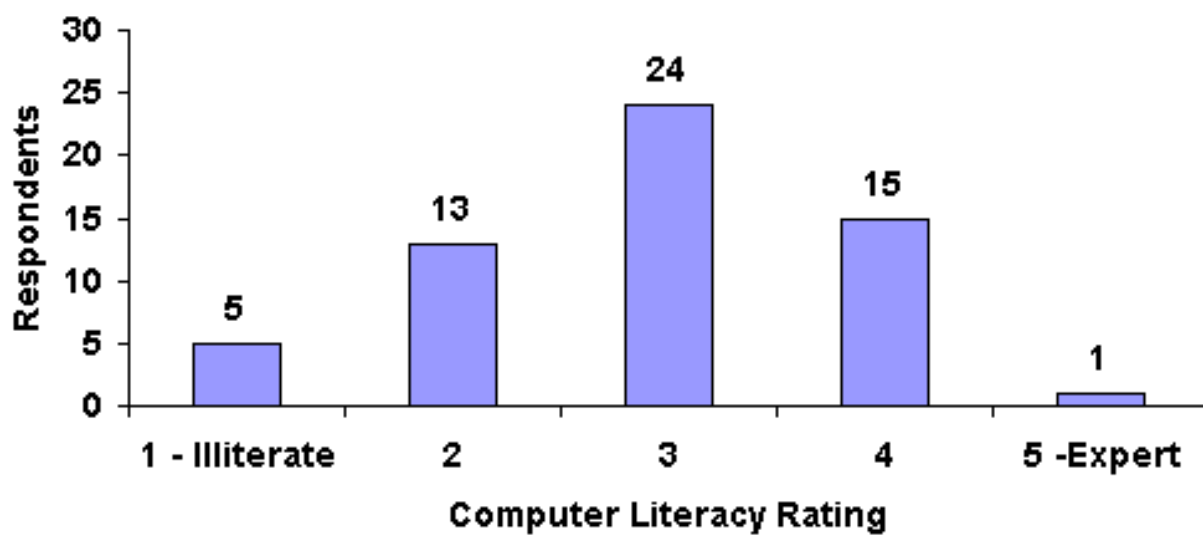
Figure 3. Desired computer literacy rating by respondents (N=58)
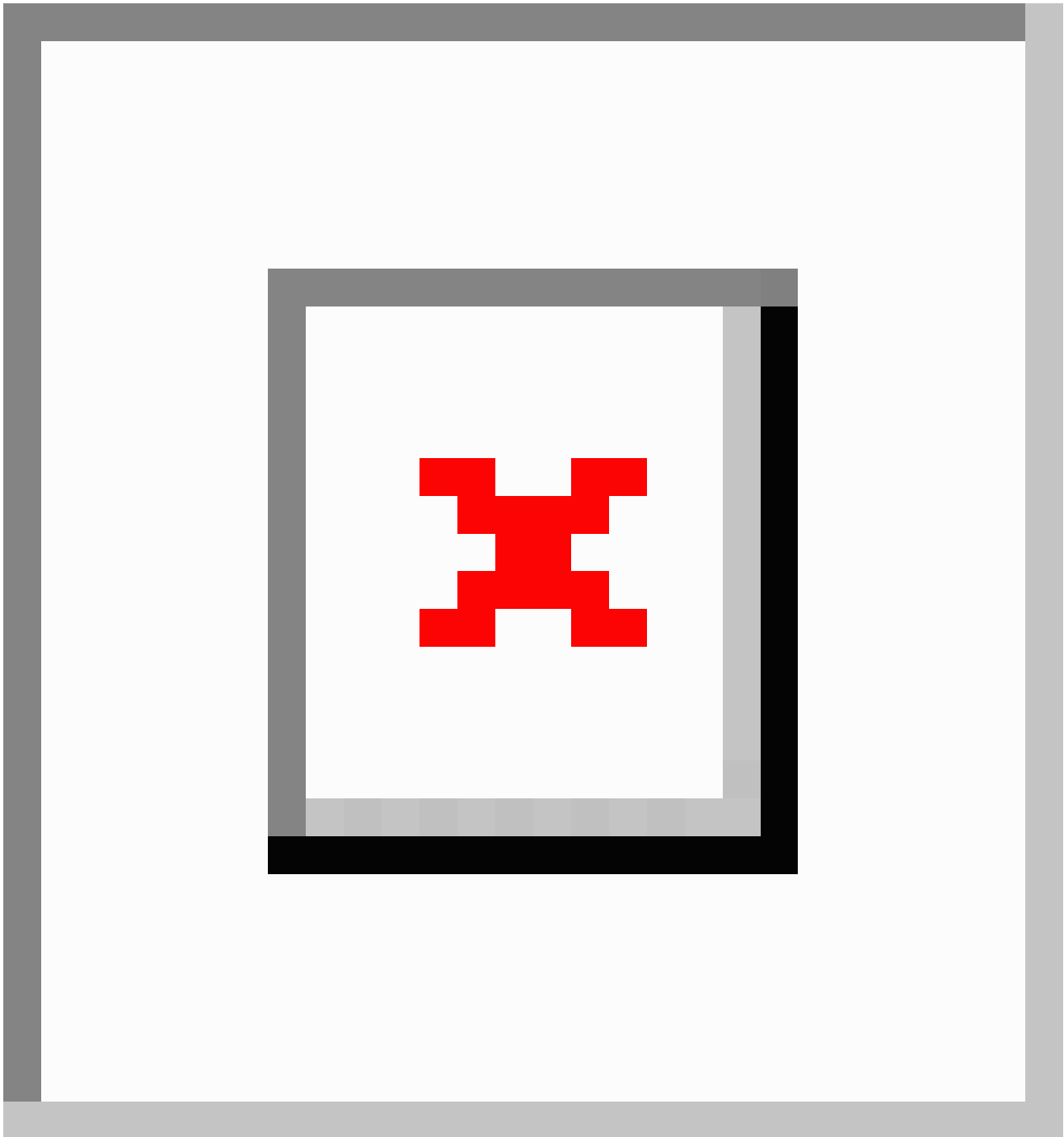
Figure 4. General computer use anxiety rating by respondents (N=57)

Communications

At the time of this survey, all pharmacists at Vancouver Hospital and Health Sciences Centre had active hospital-based e-mail accounts. All respondents stated they had the ability to receive and read e-mail with varying degrees of skill, although 4 (7%) respondents were unable to send e-mail. Other reported difficulties related to e-mail were sending attachments, 11 (19%) unable; setting up a group mailing list, 13 (23%) unable; making mailboxes for saving and organizing important e-mail messages, 19 (33%) unable; keeping copies of sent e-mail, 10 (18%) unable; and automatically sorting e-mail with filtering rules, 21 (37%) unable.

Internet Skills

Using a 5-point scale, pharmacists were asked to rate their ability to perform three basic Internet skills. The majority (46, 81%) of respondents rated themselves as "4" or greater in terms of their ability to access Web sites by typing the URL. Thirty-five (60%) rated themselves as "4" or greater in terms of ability to maintain a list of Web sites using the Web browser bookmark feature, and 12 (21%) rated themselves as a "1" (no ability). Thirty-one (54%) respondents rated themselves as "4" or greater in terms of ability to download files from online sources.

Clinical Database Information Retrieval

Skill in using search engines varied widely among the pharmacists. Eleven (19%) of those who responded were unable to use the OVID search engine, and 15 (26%) were unable to use the PubMed search engine. Fourteen (24%) respondents had expert-level ability with the OVID search engine, and 7 (12%) had expert-level ability with the PubMed search engine. The remaining respondents had varying degrees of ability with each of these search engines. Twenty-three (40%) survey participants could not explain the differences between the OVID and PubMed search engines.

Online Resources Awareness and Ability

The majority of respondents had some awareness of what online resources were available to them at our hospital for drug-related problems encountered in practice. On a 5-point scale, 43 pharmacists (75% of respondents) rated their awareness of resources as "3" or greater. Although no respondents rated themselves as having expert (i.e. "5") knowledge regarding use of online resources, 35 (61%) rated themselves as "3" or greater (Figure 5). Eleven (19%) respondents reported that they had no knowledge of what online resources to use for various drug-related problems.

Figure 5. Knowledge of online resource rating by respondents (N=57)
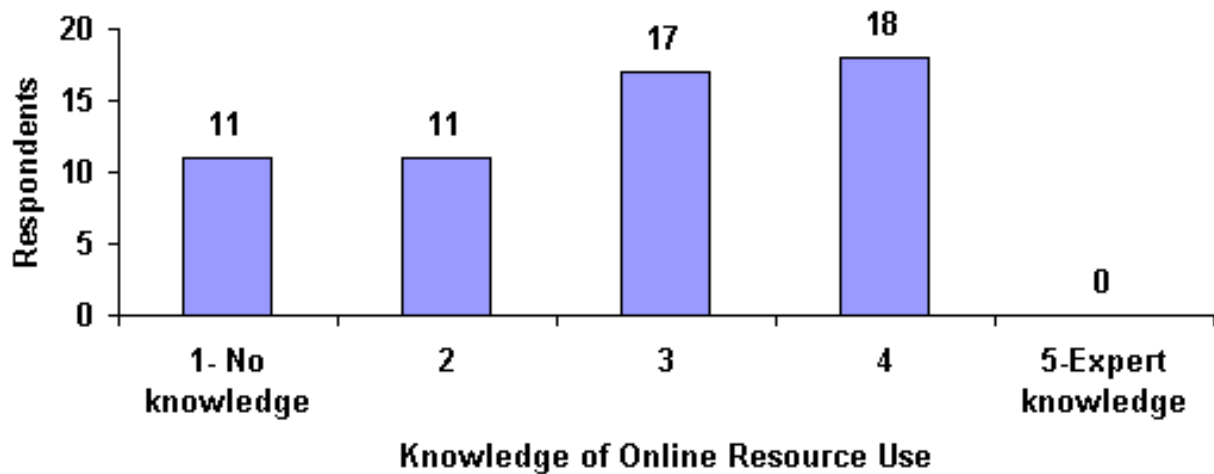
On a 5-point scale, 27 (46%) respondents rated their frequency of use of Clinical Pharmacology as "4" or greater. Fifteen (26%) respondents used this reference frequently, e.g. weekly, and 9 (16%) never used this reference. When respondents were asked to rate their ability to use this reference, the most common response was "4" (19, 33%). Eighteen (31%) respondents rated their ability to use this reference as "poor," and only 2 (3%) rated themselves as expert.

On a 5-point scale, 18 (31%) respondents rated their frequency of use of MD Consult as "4" or greater. Seven (12%) used this reference frequently, e.g. weekly, and 14 (24%) never used this reference. When respondents were asked to rate their ability to use this reference, the most common response was "poor" (21, 36%). Fifteen (26%) respondents rated their ability to use this reference as "4," and only 2 (3%) rated themselves as expert.

On a 5-point scale, only 8 (14%) respondents rated their frequency of use of UpToDate as a "4" or greater. Six (10%) respondents used this reference frequently, e.g. weekly, and 28 (48%) never used this reference. When respondents were asked

to rate their ability to use this reference, the most common response was "poor" (29, 50%). Twenty-three (40%) respondents rated their ability to use this reference as "2" or "3," and only 2 (3%) rated themselves as expert.

Anticipated Future Needs

Using a 5-point scale (1 = no need; 5 = significant need), pharmacists were asked to rate their anticipated needs for nine independent computer skills (Appendix 1). In descending rank order, respondents rated their needs as "significant" for medical database search, 31, (53%); Internet search 30, (52%); Web browser navigation 25, (43%); advanced e-mail management 21, (36%); presentation software 20, (35%); word processing 17, (29%); database software 13, (22%); statistical software 10, (17%); and spreadsheet software 10, (17%).

When asked to identify their need for general computer skill upgrading to more effectively perform their jobs, 44 (77%) respondents rated their need as "3" or greater, and 11 (19%) rated their need as "significant" (Figure 6).

Figure 6. Need to upgrade computer skills to perform job more effectively (N=57)
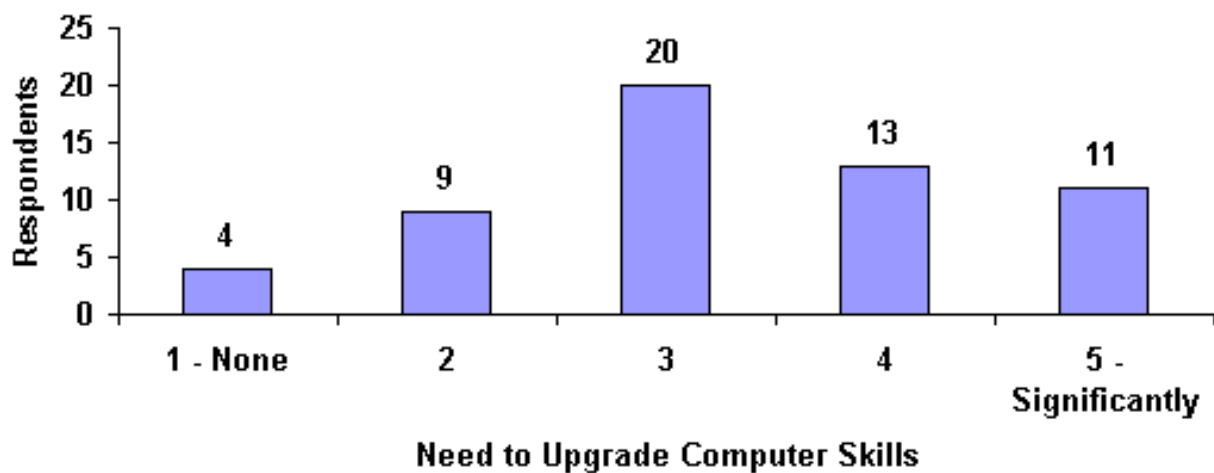
Discussion

In addition to having strong clinical skills, pharmacists must be able to use resources effectively if they are to provide optimal patient care [10]. With the introduction of computers and access to the Internet, pharmacists must also possess the necessary computer skills to efficiently manage the high volume of information now available to them. Unfortunately, a standard definition of computer literacy and valid dimensions of computer competency for pharmacy practice have yet to be delineated.

In this study, we assessed the self-reported capabilities and needs of our pharmacists in an effort to optimize our staff training and resource development strategies. To our knowledge, this is the first published report to characterize the self-reported computer skills and needs of hospital pharmacists.

Our survey responses reflect the opinions of hospital pharmacists with a broad range of education and pharmacy practice experience. We found that most respondents had home access to personal computers and regularly used computers in the work environment for drug distribution, information management, and communication purposes. Few pharmacists reported experience with handheld computers. Software use experience varied according to application. Although patient-care information software and e-mail were commonly used, experience with spreadsheet, statistical, and presentation software was negligible. The pharmacists were familiar with Internet search engines, and their use was reported to be the most common method of seeking clinical information online. Although many pharmacists rated themselves as being generally computer literate and not particularly anxious about using computers, the majority believed that they required more training to reach their desired level of computer literacy. Lack of familiarity with computer-related terms was prevalent. Self-reported basic computer skill was typically of moderate level, and varied depending on the task. Specific file management tasks were commonly described as difficult, but most respondents had little difficulty with Internet access and navigation. Respondents were generally aware of what online resources were available to them, and Clinical Pharmacology was the most commonly employed reference. In terms of anticipated needs, most pharmacists believed they needed to upgrade their computer skills. Although respondents rated their skills in medical database and Internet searching as high, these skills were identified as in greatest need of further improvement for the purposes of improving practice effectiveness.

Although it is desirable for pharmacist practitioners to graduate with a minimum set of computer and information management skills, informatics remains an uncommon component of most pharmacy or medical school curricula [11,12]. Poikonen recently reported that of 86 US PharmD programs surveyed, the use of computers to assist in treatment decision-making occurred in less than half the schools that responded. Only 13% of schools employed an informatics faculty member [11]. The majority of our pharmacist members graduated from our local university (University of British Columbia) where informatics is not a formal component of the core undergraduate or graduate programs. In addition, the majority of respondents stated they had received no formal computer training. This probably affected the level of computer skills reported by this cohort.

Our study suffers from some methodological limitations. The anonymous survey involved a self-reporting of computer skills and needs; thus, the results must be considered subjective only. We sought the general impressions of our pharmacists, and utilized a simple rating scale in an attempt to quantify the respondents' perceptions of their abilities. We did not define all options between extreme or absolute scale points on the questionnaire, and this may have produced a tendency for respondents to select intermediary scores. No additional objective measurements (e.g. tests, observation of actual computer activities) were undertaken, nor was a validated survey available for use. Accordingly, we cannot directly compare our results with those of any other group. Although we achieved a relatively good response rate, the survey nevertheless involved a small non-randomized local sample of hospital pharmacists from two sites of a single health-care organization. Therefore, extrapolation of results to other practice environments must be done with caution.

In summary, this study has provided us with valuable insight into the current status of the computer skills and needs of our pharmacists. We will utilize this information to address the applied informatics needs of our members and help them use technology to enhance their knowledge, manage patient-care information, and improve their practice effectiveness. We recommend other groups consider undertaking a similar assessment of computer skills and needs, particularly if considering the implementation of an applied informatics program.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Survey Form [PDF File, 79KB - jmir_v6i1e11_app1.pdf]

References

1.   Balen RM, Miller P, Malyuk DL. Medical informatics: pharmacists' needs and applications in clinical practice. J Inform Pharmacother 2000;2:306-318 [FREE Full text]

2.   Agho AO, Williams AM. Actual and desired computer literacy among allied health students. J Allied Health 1995;24(2):117-126. [Medline: 95370072]

3.   ; SPSS Inc. SPSS. Version 10.1. URL: http://www.spss.com/ [accessed 2004 Mar 15]

4.   Staggers N. The Staggers Nursing Computer Experience Questionnaire. Appl Nurs Res 1994 May;7(2):97-106. [Medline: 94304196] [doi: 10.1016/0897-1897(94)90040-X]

5.   Debehnke DJ, Valley VT. Assessment of the current computer literacy and future computer needs of emergency medicine residents and faculty. Am J Emerg Med 1993 Jul;11(4):371-373. [Medline: 94030241] [doi: 10.1016/0735-6757(93)90170-G]

6.   Graveley EA, Lust BL, Fullerton JT. Undergraduate computer literacy. Evaluation and intervention. Comput Nurs 1999;17(4):166-170. [Medline: 99354547]

7.   Saranto K, Leino-kilpi H. Computer literacy in nursing: developing the information technology syllabus in nursing education. J Adv Nurs 1997 Feb;25(2):377-385 [FREE Full text] [Medline: 97196925] [doi: 10.1046/j.1365-2648.1997.1997025377.x]

8.   Houston C. Computer literacy self assessment. URL: http://edtech.cebs.wku.edu/~chouston/LME448/complitsurvey.htm [accessed 2002 May]

9.   Jerant AF, Lloyd AJ. Applied medical informatics and computing skills of students, residents, and faculty. Fam Med 2000 Apr;32(4):267-272. [Medline: 20244231]

10. Martin AE, Stumpf JL, Ryan ML. Assessing pharmacists' competence in clinical information retrieval. Am J Health Syst Pharm 1996 Dec 15;53(24):2957-2958. [Medline: 97129650]

11. Poikonen JC. Comparison of medical and pharmacy informatics curricula [abstract]. Presented at: American Association of Colleges of Pharmacy Annual Meeting; 2000; San Diego, USA p. 211.

12. Buckeridge DL, Goel V. Medical Informatics in an undergraduate curriculum: a qualitative study. BMC Medical Informatics and Decision Making 2000;2:306-318 [FREE Full text]

Abbreviations

CSU: Clinical services unit

PCIS: Patient care information system

VHHSC: Vancouver Hospital and Health Sciences Centre

Original Paper

DietPal: A Web-Based Dietary Menu-Generating and Management System

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Abstract

Background: Attempts in current health care practice to make health care more accessible, effective, and efficient through the use of information technology could include implementation of computer-based dietary menu generation. While several of such systems already exist, their focus is mainly to assist healthy individuals calculate their calorie intake and to help monitor the selection of menus based upon a prespecified calorie value. Although these prove to be helpful in some ways, they are not suitable for monitoring, planning, and managing patients' dietary needs and requirements. This paper presents a Web-based application that simulates the process of menu suggestions according to a standard practice employed by dietitians.

Objective: To model the workflow of dietitians and to develop, based on this workflow, a Web-based system for dietary menu generation and management. The system is aimed to be used by dietitians or by medical professionals of health centers in rural areas where there are no designated qualified dietitians.

Methods: First, a user-needs study was conducted among dietitians in Malaysia. The first survey of 93 dietitians (with 52 responding) was an assessment of information needed for dietary management and evaluation of compliance towards a dietary regime. The second study consisted of ethnographic observation and semi-structured interviews with 14 dietitians in order to identify the workflow of a menu-suggestion process. We subsequently designed and developed a Web-based dietary menu generation and management system called DietPal. DietPal has the capability of automatically calculating the nutrient and calorie intake of each patient based on the dietary recall as well as generating suitable diet and menu plans according to the calorie and nutrient requirement of the patient, calculated from anthropometric measurements. The system also allows reusing stored or predefined menus for other patients with similar health and nutrient requirements.

Results: We modeled the workflow of menu-suggestion activity currently adhered to by dietitians in Malaysia. Based on this workflow, a Web-based system was developed. Initial post evaluation among 10 dietitians indicates that they are comfortable with the organization of the modules and information.

Conclusions: The system has the potential of enhancing the quality of services with the provision of standard and healthy menu plans and at the same time increasing outreach, particularly to rural areas. With its potential capability of optimizing the time spent by dietitians to plan suitable menus, more quality time could be spent delivering nutrition education to the patients.

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Introduction

Planning nutritious and appetizing menus is a complex task that researchers have tried to computerize since the early 1960s [1,2]. Although a number of menu-planning systems have been developed in recent years, these systems are mainly used to assist healthy individuals calculate their calorie intake and to help monitor the selection of menus based upon a prespecified calorie value. Also, some of these systems do not address the standard practice and procedure employed by dietitians during consultations with patients. Planning nutritious menus for patients, however, is not the same as planning menus for healthy individuals. Patients require advice and directions from dietitians in designing their menus. Dietitians on the other hand, during the course of consultation with a patient, may want to refer, for example, to the patient's medical and dietary history, dietary recall, biochemical data, and anthropometric data. to construct a suitable dietary plan and menu for patients. For example, a suitable menu for a diabetic patient is constructed based on the patient's calorie requirement determined using anthropometric data such as weight and height. The patient's blood sugar control is examined to decide on refined-sugar allowances. Finally, obtaining the dietary history of a particular patient is necessary in order to consider factors such as food habit and preferences. Therefore, an ideal menu-planning system should not only contain information about foods and menus but should also incorporate other related information for the purpose of decision making by dietitians (as discussed earlier).

Realizing the limited capabilities of existing systems, this paper, therefore, describes the development of an automated Web-based menu-generating system, according to a standard procedure and practice adhered to by dietitians in managing patients, and based upon a user-needs study conducted prior to the development of the system. This project is a collaboration between the Faculty of Information Science and Technology and the Faculty of Allied Health Sciences (see "Acknowledgements" for funding information).

At the moment, the system is intended for use by dietitians and health professionals to extract patients' dietary recalls and to design suitable menus based on a patient's dietary habits and nutritional requirements.

Related Research and Development

As previously mentioned, there have been a number of menu-generating systems or dietary-analysis programs available, either implemented as a Web-based application [3- 8] or as a traditional information system [9- 11].

A few systems reviewed—such as Case-Based Menu Planner (CAMP) [12], Pattern Regulator for the Intelligent Selection of Menus (PRISM) [13], and CAMP Enhanced by Rules (CAMPER) [11]—employed techniques from the field of artificial intelligence (AI):

- CAMP employs the case-based reasoning (CBR) technique to suggest menus to users. CAMP uses past menus that were compiled from reputable sources and modified as needed to ensure that they satisfy the RDIs (Reference Daily Intakes) and the Dietary Guidelines of Americans and Aesthetic standards [10]. The menu generated by CAMP is based upon nutrient composition, type of servings, and the number of snacks.
- PRISM uses rules to generate menus. The rules are mainly concerned with menus and meal patterns.
- CAMPER is an integration of the techniques employed by CAMP and PRISM. Therefore, apart from using the case-based reasoning technique, CAMPER uses rules or "what if" analysis module to enhance the menu suggestion activity.

The main interesting and distinguishing feature exhibited by our system as compared to the other reviewed systems is its use of the complete dietary-management system currently adhered to by dietitians in Malaysia, particularly at the National University Hospital of Malaysia. In addition, our system exploits current advanced Internet technology, by considering the system's implementation as a Web-based application. This, to a certain extent, increases the outreach of the system for use by dietitians and health professionals within the same hospital or at other locations. The system is also capable of storing and organizing patients' dietary records and other health-diet related information. This capability would allow dietitians to effectively evaluate or monitor the patients' dietary changes throughout the period of consultations.

Methods

User Information Needs Study and Functional Specification

Prior to the development of the system, a user-needs study was conducted among dietitians within the Klang Valley in Malaysia [14].. The user-needs study included 2 independent surveys. The first survey of dietitians was on computer literacy and utilization, information seeking activities, and assessment of information required for dietary management and evaluation of compliance towards a dietary regime. The second survey consisted of semistructured interviews with a subsample of dietitians in order to extract the knowledge and workflow of a menu-suggestion process.

Development of DietPal

DietPal was developed as a Web-based system in order to increase outreach, particularly in rural areas. The main scripting language used is Active Server Pages (ASP) together with other scripting languages, mainly VBScript and JavaScript.

The development of DietPal took into account the key findings of the user-needs study and the consultation flow currently adhered to by dietitians.

Post-evaluation

An initial post-evaluation has been conducted by distributing a written survey among 10 dietitians who are directly involved in the management of patients from the National University of Malaysia Hospital.

Results

User Information Needs Study and Functional Specification

In the first survey, questionnaires were posted to 93 clinical dietitians registered with the Malaysia Dietitians' Association; 52 subjects (56%) responded. The questionnaire contained the question "Which information items do you seek to support decision making and evaluation of a dietary regime", with the 10 items listed in Table 1 and participants asked to assign a rating score of 1 to 5 (1 = least likely seek, 5 = most likely seek) was used to identify the information needed to. In a similar way, participants were asked which information items they needed in order to monitor the compliance of a patient (Table 2).

Table 1 and Table 2 present part of the results obtained from this user-needs study. Because the questionnaire was self administered not all items were responded to by all 52 subjects; thus, missing data was unavoidable.

Table 1. Results of the information-needs survey of 52 dietitians

Information Need	Mean Score ± SD*
Medical diagnosis	4.80 ± 0.45
Current body height and weight	4.69 ± 0.65
Nutrient requirement	4.57 ± 0.88
Biochemical values	4.55 ± 0.86
Dietary recall	4.53 ± 0.86
Weight	4.18 ± 1.01
Medical history†	4.14 ± 0.95
Medication	3.71 ± 1.15
Allergy	3.35 ± 1.32
Supplement	3.31 ± 1.24

* Frequency score: 1= least likely seek, 5=most likely seek.

† N = 50.

Table 2. Results of the indicators for patient compliance survey

Data Type*	N	Mean Score ± SD
Biochemical values	51	4.69 ± 0.62
Food intake change	52	4.63 ± 0.60
Compliance to diet regime	52	4.62 ± 0.57
Weight change	51	4.61 ± 0.57
Clinical parameters	49	4.53 ± 0.65
Changes of knowledge/behavior	52	3.98 ± 1.09
Physical activities	50	3.76 ± 1.13
Changes of medication	50	3.14 ± 1.25

* Frequency score: 1=most frequent, 5=least frequent.

Based upon the results presented in Table 1 and Table 2, the most common information used to support decision making according to the mean of scores were medical diagnosis, current body weight and height, nutrient requirement, biochemical values, and dietary recall.

The most relevant indicators for monitoring patient compliance were reported to be biochemical values, food intake changes, compliance to diet regime, and weight change.

The second survey involved ethnographic observation of 14 clinical dietitians from government, university hospitals, and private hospitals doing individual dietary counseling. This study was similar to an information-engineering activity, in which the task was to extract the knowledge and the workflow of generating a menu for patients. In this case, 14 dietitians were interviewed and observed while conducting their daily activities. The survey was also aimed at validating the results of the first survey and determining at which stage of the menu-suggestion process the "frequently sought after" information items are being used. The result of this survey is a workflow of a menu-suggestion process currently used by dietitians in Malaysia, as illustrated in Figure 1.

Figure 1. The workflow of menu-suggestion activity, as determined by observing and interviewing dietitians in Malaysia. A solid line with single arrowhead refers to flow of menu-suggestion activity. A dotted line with double arrowhead refers to the process of recording information or moving a record to the respective forms or data repository. A dashed-plus-dotted line with single arrowhead refers to the process of retrieving previous/existing data
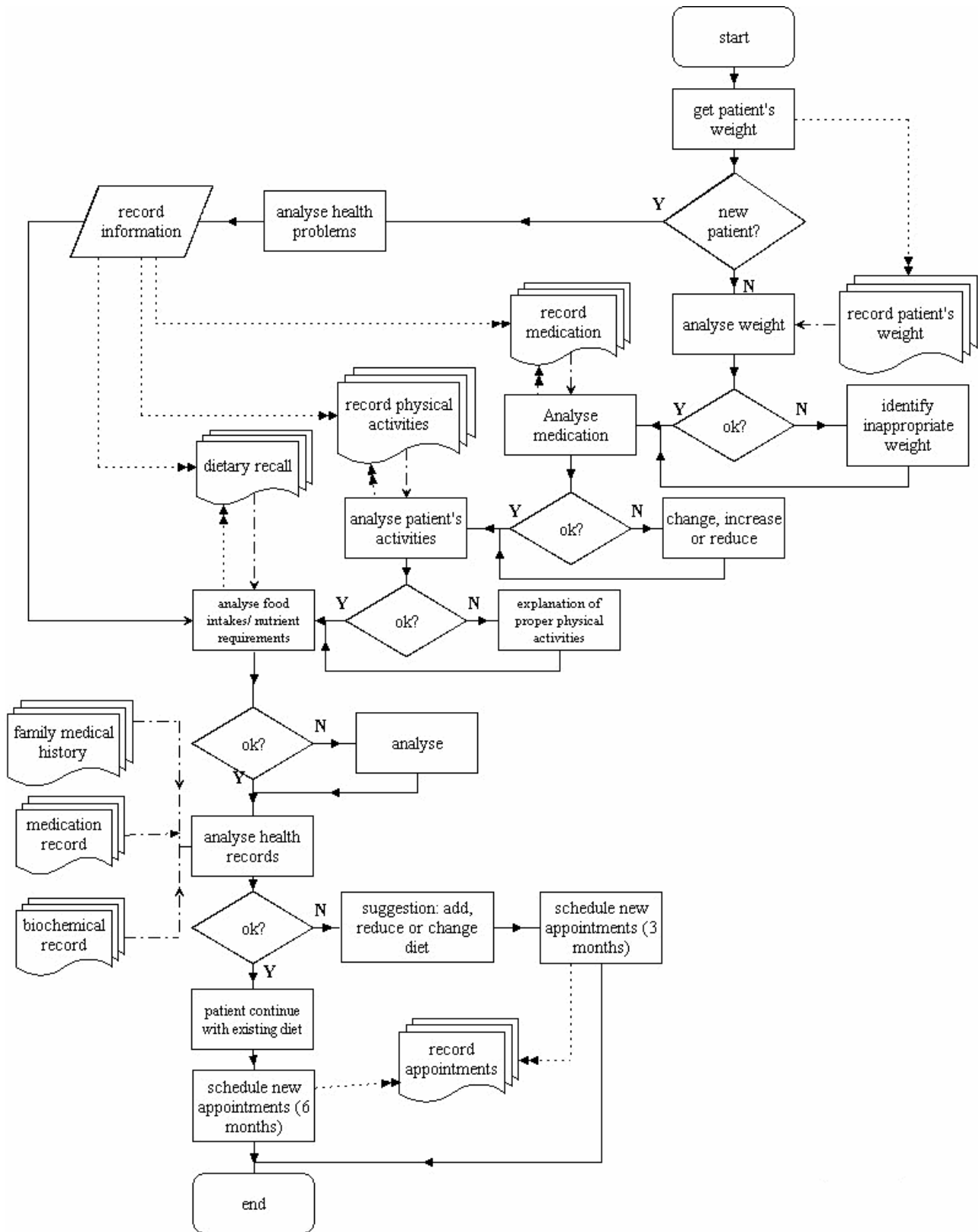
Menu Generation and Management with DietPal

As illustrated in DietPal's system architecture (Figure 2), the system consists of 5 databases with 2 main modules, the Management module and the Menu Generating Module. The Management module is designed to manage information relating to patients' personal and medical information and to assess patients' compliance to dietary regime. The Menu Generating module is designed to interactively assist users in planning suitable menus and diet plans for patients. The Patient database is used to store the patient's information, which includes the personal data, anthropometric and biochemical data, medical record, and information on dietary recall. This database is heavily used in the Management module. The Food Composition database consists of information about foods and nutrient composition, extracted from the Malaysian Food Composition Tables for macronutrients and micronutrients. This database is used for food-analysis purposes. The Diet Plan/Menu database consists of therapeutic menus for specific diseases; the menus were obtained from reputable sources and have been approved by dietitians.

When using DietPal for an existing patient, the dietitian is first required to update the anthropometric data, particularly the body weight; this is to record any important patient changes since the previous meeting. If current biochemical data is available, such data will also be recorded by the dietitian; this is to monitor the patient progress so as to evaluate patient compliance to the previously-suggested menus. Information regarding any new medical diagnosis and current medication, if any, will also be recorded. For new patients, the dietitian is required to formally register the patients with the system; information such as name, date of birth, address, occupation, and other information similar to that for existing patients will be recorded.

Figure 2. The DietPal system architecture

The next step involves acquiring the patient's dietary recall in order to assess the patient's compliance to a dietary regime as well as to assist dietitians in planning suitable menus based on the patient's food habits. In normal circumstances, the dietitian will record the patient dietary recall of up to 7 days of food intake. In this case, the dietitian will interview the patient and will select the available food stored in the food-composition database. For cases in which the food is not available in the database, the dietitian will choose other similar types of food based on calorie content. DietPal will automatically calculate the level of macronutrients and micronutrients for an average of 1 day. Apart from that, DietPal also allows the user to compare the level of macronutrients with the individual calorie requirement based on Basal Metabolic Rate (BMR), physical activity, and stress factor, while the micronutrient intake is compared with the Malaysian Recommended Dietary Allowance (RDA) [15] for nutrients determined according to the patient's sex and age group. The task of dietary recall is important for assessing the patient's compliance to the dietary regime, but, because this process is time consuming, it can be passed over

by the dietitian, who can go directly to the menu-generating function.

The menu generation starts with DietPal automatically calculating the Body Mass Index (BMI) and providing a suggestion as to whether the patient is, for example, normal, obese, or underweight. Simple rules are used to make such a decision. Anthropometric information is also displayed by DietPal in order to assist dietitians in making decisions. Two methods can be used to automatically generate the energy requirements of each individual patient:

- Predictive equation to estimate energy requirement based on Basal Metabolic Rate (BMR) (Table 3), stress factor (Table 4), and activity factor (Table 5). The energy requirement is estimated using the following formula [16]: Energy requirement = BMR × stress factor × activity factor.
- Quick method, based on the following formula: Energy requirement = weight (kg) × quick method factor (kcal/kg)

Values of the quick method factor based on weight status and physical activity are shown in Table 6 [17].

Table 3. Equations to predict Basal Metabolic Rate (BMR)

Age Range (Years)	Equation for Men*	Equation for Women*
15-18	17.6W + 656	13.3W + 690
18-30	15.0W + 690	14.8W + 485
30-60	11.4W + 870	8.1W + 842
> 60	11.7W + 585	9.0W + 656

* W = weight (kg)

Table 4. Stress factor in clinical situation

Clinical Situation	Stress Factor
Starvation	0.85
Elective surgery	1.05-1.15
Sepsis	1.20-1.40
Head injury	1.30
Trauma	1.40
Inflammation	1.50
Burns	2.0

Table 5. Activity factor

Activity	Activity Factor
Bed bound immobile	1.0-1.2
Out of bed	1.3-2.0

Table 6. Quick method factor

Physical Activity	Quick Method Factor		
	Overweight	Normal Weight	Underweight
Sedentary	20-25 kcal/kg weight	30 kcal/kg weight	35 kcal/kg weight
Moderate	20-25 kcal/kg weight	35 kcal/kg weight	40 kcal/kg weight
Marked	20-25 kcal/kg weight	40 kcal/kg weight	45 kcal/kg weight

Once the energy requirement has been determined, the macronutrient requirement will be calculated (the energy is distributed into 3 macronutrients, see Table 7). In this case, the dietitian will provide the percentage of carbohydrate, protein, and fat (C-P-F) and DietPal will automatically calculate the kilocalories and grams of carbohydrate, protein, and fat according to the energy requirement of the particular patient. Values in Table 7 are the default values provided by the system;

they are derived from the Malaysian Dietary Guidelines [18]. Dietitians, however, are allowed to alter these values based on patients' requirement as illustrated in Figure 3. If the total percentage of all nutrients exceeds 100% or is below 100% an error message is provided to the user. Based on these nutrient percentages, the kilocalories and grams of the nutrient are automatically generated by the system.

Table 7. Contribution of macronutrients to total calories

Nutrient	Percentage of Total Calories*
Carbohydrate	55
Protein	15
Fat	30

* Default values provided by the system; derived from Malaysian Dietary Guidelines.

Figure 3. An interface allowing dietitians to edit the contributions of macronutrients
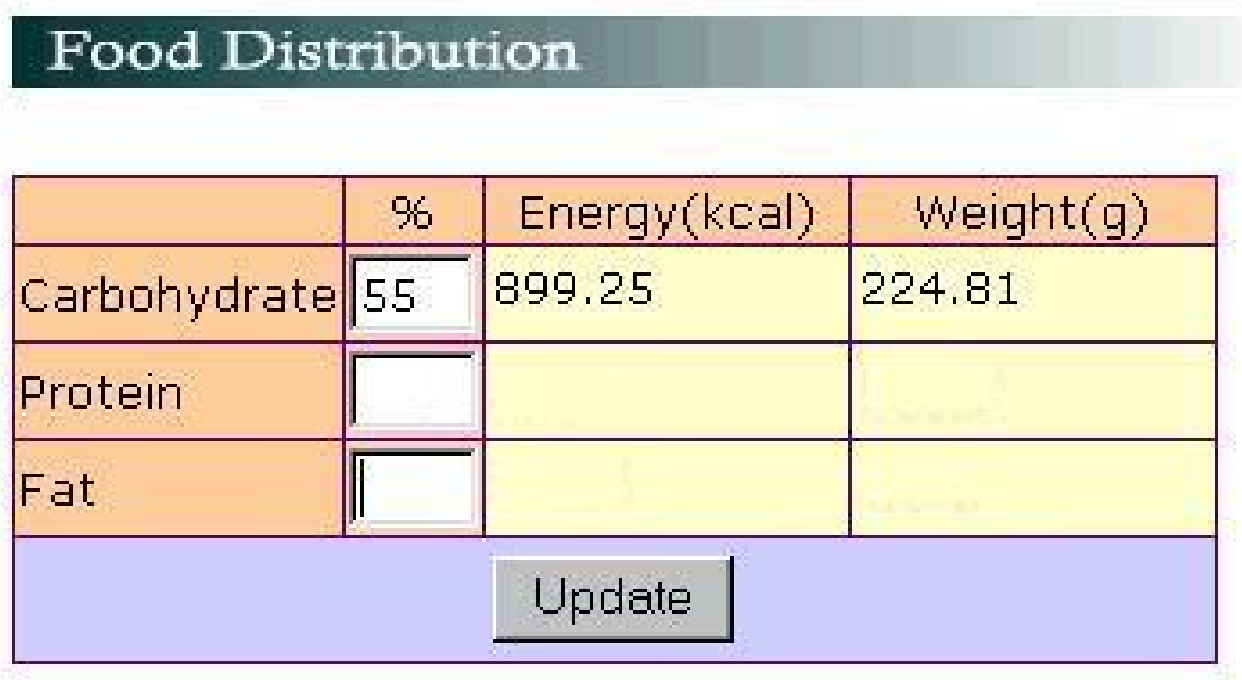
The next step requires the dietitian to design the exchange table by food groups and by meals. An exchange table describes the portions of each food group based on a prefixed amount of carbohydrate, protein, and fat. For example, 1 exchange of food from the cereals food group contains 15 g of carbohydrate, 2.0 g of protein, and 0.5 g of fat. In this case, DietPal will first suggest an exchange table based on the standard calculation currently practiced by Malaysian dietitians. The user is allowed

to alter any exchange portions according to the patient's needs; DietPal will update the amount of carbohydrate, protein, fat, and energy accordingly. Once the exchange table by food group has been successfully produced, the dietitian will continue with the design of an exchange table by meal. In this case the dietitian is required to fill in the exchange portions for the relevant mealtimes. DietPal will detect any inconsistency that might

occur, such as if the distributed amount of exchange portions is not equal to the total exchanges.

As an alternative to the aforementioned process, the dietitian can retrieve the standard existing exchange table by food and by meal stored in the Diet Plan database. To date, DietPal has a number of diet plans ranging from 1200 kcal to 2000 kcal designed by dietitians from the Faculty of Allied Health Sciences of the National University Hospital of Malaysia. Figure 4 illustrates the output of the exchange table by food and by meal for the 1600 kcal standard diet plan. The distribution of the macronutrients are based on a prefixed range of exchanges of each food group (ie, cereal, 8-14 exchanges; fruits, 2 exchanges; skim milk, 1-2 exchanges; vegetables, minimum 2 servings; meat, 1-2 exchanges; fish, 2 exchanges; and oil, 6-10 exchanges). The use of existing diet plans greatly reduced the time for designing such food-distribution tables.

The menu suggestion will be made after all the aforementioned steps have been completed. There are currently 2 available approaches offered by DietPal—either dietitians design the menu based upon the nutrient requirement and exchange tables or they can retrieve and reuse preexisting menus from the Case Base. From the exchange allowances of each food group (Figure 4), the dietitian will then be able to generate a suitable menu based on the Malaysian Food Composition Table. Alternatively, the dietitian can retrieve preexisting menus based upon the nutrient requirement and the disease state of the patient. The retrieved menu can be edited or altered by dietitians according to the suitability of the patient. The output menu—either manually-designed or retrieved from the Case Base—will be stored in the Case Base for future use. Dietitians can design or retrieve more than 1 menu for the patient. Figure 5 illustrates an example of a menu plan generated using DietPal.

Figure 4. Exchange table by food group and by meal for 1600 kcal/day

Figure 5. An example of menu/diet plan for 1600 kcal/day designed by using DietPal. Cho refers to carbohydrate and Pro refers to protein

Suggestion Menu
Food Detail

	Food	Measurement	Kcal	Cho	Pro	Fat
Breakfast						
1	Milk, powder, skim	1.5 table spoon heap	42	6.83	3	0.3
2	Bread, white	4 piece[LxWxT, 10.5x10.5x1.2cm]	292	60	11.2	1.2
3	Margarine	1.5 tea spoon level	69	0.15	0.15	7.5
	Total		403	66.98	14.35	9
Lunch						
1	Rice, cooked	1.5 cup	195	45	3.6	0.15
2	Mackerel, Spanish	1 piece	70	0	14	1.6
3	Apple Red	1 whole	64	15	0.3	0.5
4	Oil, palm olein	1.5 tea spoon heap	67.5	0	0	7.5
	Total		396.5	60	17.9	9.75
Afternoon Tea						
1	Milk, powder, skim	2 table spoon heap	56	9.1	4	0.4
2	Biscuit, cream crackers	9 Pieces(square, LxWxT, 5x5x0.2cm)	132	22.5	2.7	3.9
	Total		188	31.6	6.7	4.3
Dinner						
1	Rice, cooked	2 cup	260	60	4.8	0.2
2	Henn Egg, Whole	2 whole	168	1	14	12
3	Papaya	1 slice	74	15	3.2	0.2
4	Oil, palm olein	2 tea spoon heap	90	0	0	10
	Total		592	76	22	22.4
	Total(Overall)		1579.5	234.58	60.95	45.45

Medical professionals of health centers in rural areas where there are no designated qualified dietitians will find the preexisting menus useful for advising patients with certain disease problems. The menu designed is only suitable for nonvegetarians, as vegetarianism is not prominent within the Malaysian society.

The functionalities of DietPal are distributed to a number of different levels of menus (pages) as illustrated in Figure 6, which correspond to the menu-suggestion activities previously described.

Figure 6. Multiple levels of menus in DietPal
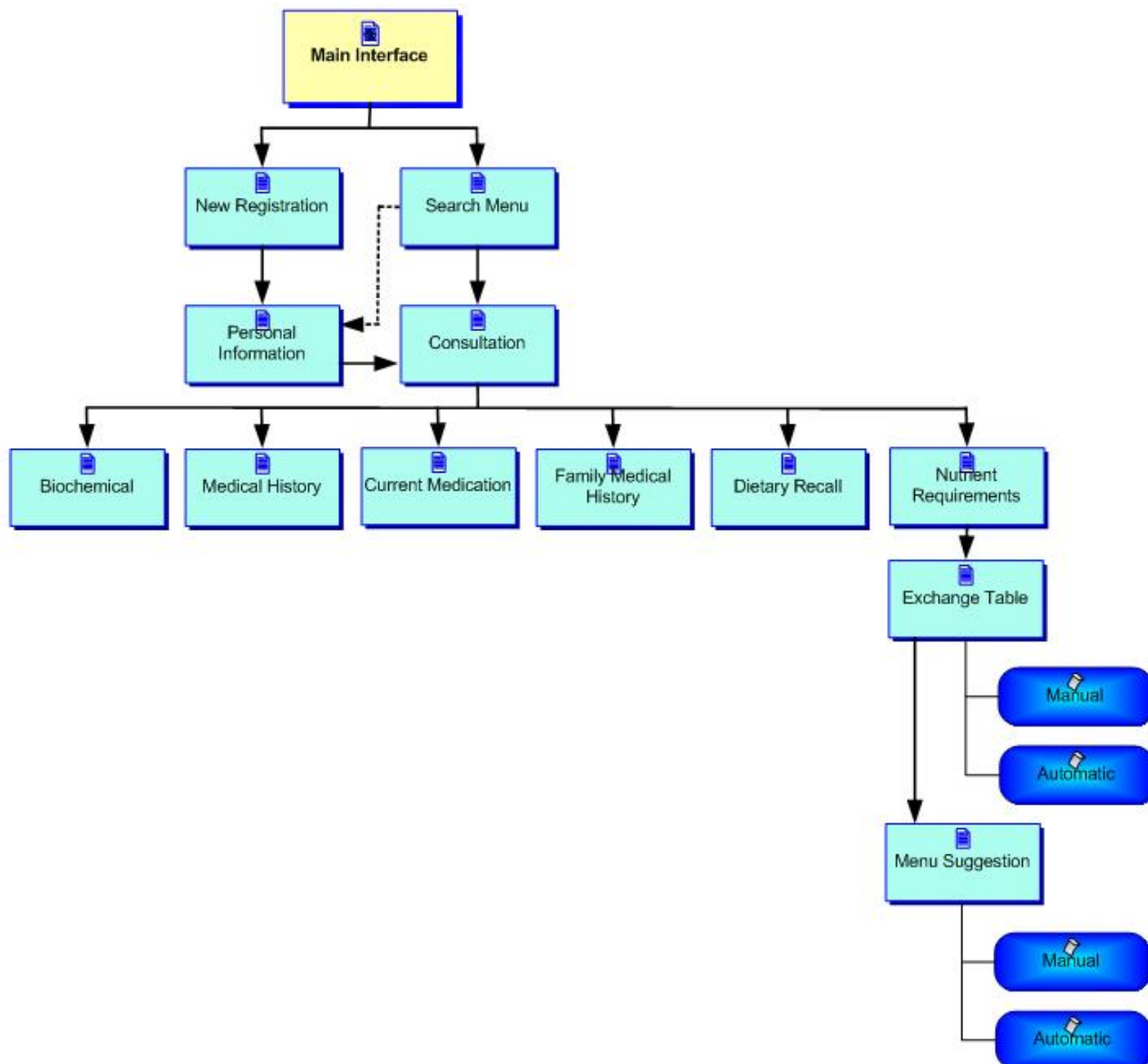
Table 8. Results of the post evaluation among 10 dietitians from the National University of Malaysia Hospital

Category	Ratings by 10 Dietitians*										
	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10	Average
1. System usability											
Personal data	4	5	2	3	4	4	5	4	3	5	3.9
Consultation	3	5	3	3	4	4	5	4	4	5	4.0
Biochemical	3	5	2	4	4	4	3	4	4	5	3.8
Medical history	3	2	2	4	4	4	4	4	4	5	3.6
Family medical history	4	5	2	3	4	4	4	4	4	-	3.8
Current medication	4	5	3	3	4	3	3	4	4	5	3.8
Dietary recall	3	5	3	2	4	4	2	5	3	4	3.5
Nutrient/Energy requirements	4	5	3	4	4	5	5	5	4	5	4.4
Exchange table by foods	4	5	3	3	4	5	5	5	4	5	4.3
Exchange table by meals	4	5	3	3	4	4	5	4	4	5	4.1
Menu suggestion	2	5	2	-	4	3	3	4	4	5	3.6
Average of system's usability											**3.9**
2. Organization of modules	4	5	3	-	4	3	4	5	2	5	3.9
3. System efficiency	3	5	2	3	4	5	4	5	3	5	3.9
4. System's accuracy	4	2	3	3	4	5	4	4	3	5	3.7
5. Satisfy user's requirement	4	5	3	4	4	5	4	4	4	5	4.2

* Ratings scale: 1 = strongly disagree/strongly dissatisfied; 2 = disagree/unsatisfied; 3 = average; 4 = satisfied/agree; 5 = strongly agree/strongly satisfied

Post-evaluation

A preliminary evaluation has been conducted among 10 dietitians who are directly involved in the management of patients from the National University of Malaysia Hospital and who used the system. The result of this evaluation is illustrated in Table 8, where scale = 1 represents strongly disagree/unsatisfied and scale = 5 represents strongly agree/satisfied. The categories used during evaluation were derived from [19- 21].

Results from Table 8 show that the system scores above average for all the categories evaluated, with *satisfy user's requirement* scoring the highest marks. These results indicate that on average dietitians are satisfied with the overall capability of the system to generate and manage dietary menus.

Discussion

The adoption of Internet- or Web-based technology in health-related applications is still lagging well behind adoption in other fields [22]. It is expected that if communications through the Internet and the World Wide Web are looked into seriously, the efficiency of delivering health care and services could be increased [23].

DietPal is a dietary menu generation and management system for patients, with simple intelligent capabilities to design and generate suitable diet plans and menus based upon the patient's energy requirement. Comparing this system with other similar Web-based systems—such as the Menu Planner developed by the National Health, Lung and Blood Institute (NHLBI) [6]; the

Nutrition Analysis Tool (NAT) [7], a public service system provided by the Food Science and Human Nutrition Department at the University of Illinois; and DietSite.com [8], provided by Dietsite.com Inc—the system exhibits a few distinguishing features:

- capacity to store and retrieve historical data related to a patient, which can be used to assess the patient's compliance to the dietary regime
- retrieval of preexisting menus that suit the requirements of an existing patient
- capacity to monitor the progress of each patient based upon the menu suggested

More rigorous testing and evaluation of the system is currently ongoing. Based on the preliminary experiences reported here, we think that it has the potential to provide the following significant contributions:

- Assist in enhancing the quality of health services and improving the outreach in urban and, particularly, rural areas with minimal costs.
- Provide standards for healthy menus for patients. Hospitals and clinics in rural areas in particular, therefore, will be able to access an up-to-date database specifying the needs of certain patients.
- Optimize time spent by dietitians to calculate nutrient intake and energy requirements, and to generate exchange tables and menus. Thus, dietitians will have more time to deliver nutrition education to patients. A cost-effectiveness study on the usage of the system among dietitians or health professionals will be conducted.

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Our ongoing work includes applying artificial-intelligence techniques to intelligently generate suitable menus for patients with certain diseases such as diabetes, hyperlipidaemia, obesity, and hypertension. We are exploring the case-based reasoning technique, where a new problem is solved by finding similar past cases, and reusing them in the new problem situation [24]. Although such a technique has been used in CAMP [12] and CAMPER [11], our approach differs from those two in the following aspects:

- We will consider the 4 major diseases (diabetes, hyperlipidaemia, obesity, and hypertension) in generating the required diet plans or menus.
- As Malaysia is a multiracial country (eg, Malay, Chinese, Indian), we need to consider menus according to the respective ethnicities.
- We will consider the patient's dietary recall as well as the patient's dietary exchanges in providing suitable menus.

Acknowledgments

Conflicts of Interest

None declared.

References

1. Balintfy JL. Menu planning by computer. Communications of the ACM 1964;7(4):255-259. [doi: 10.1145/364005.364087]
2. Eckstein EF. Menu planning by computer: the random approach. J Am Diet Assoc 1967 Dec;51(6):529-533. [Medline: 68045973]
3. ; Center for Nutrition Policy and Promotion, US Department of Agriculture. Interactive Healthy Eating Index (IHEI). URL: http://www.usda.gov/cnpp/ihei.html [accessed 2003 Nov 4]
4. ; Fitday.com. Home page. URL: http://www.fitday.com/ [accessed 2003 Nov 4]
5. ; Cyberdiet. Home page. URL: http://www.cyberdiet.com/ [accessed 2003 Nov 4]
6. ; Heart, Lung, and Blood Institute; National Institutes of Health. Interactive menu planner. URL: http://hin.nhlbi.nih.gov/menuplanner/ [accessed 2002 Aug 12]
7. ; National Institutes of Health. Nutrition Analysis Tool 2.0. URL: http://nat.crgq.com/ [accessed 2002 Aug 14]
8. ; DietSite.com. Home page. URL: http://www.dietsite.com/ [accessed 2002 Sep 21]
9. Marling CR, Petot GJ, Sterling L. Integrating case-based and rule-based reasoning to meet multiple design constraints. Computational Intelligence 1999;5(3):308-332. [doi: 10.1111/0824-7935.00095]
10. Petot GJ, Marling C, Sterling L. An artificial intelligence system for computer-assisted menu planning. J Am Diet Assoc 1998 Sep;98(9):1009-1014. [Medline: 98412124] [doi: 10.1016/S0002-8223(98)00231-4]
11. Sterling L, Petot GJ, Marling CR, Kovacic K, Ernst G. The role of common sense knowledge in menu planning. Expert Systems with Applications 1996;11(3):301-308. [doi: 10.1016/S0957-4174(96)00046-2]
12. Marling CR. Integrating case-based and rule-based reasoning in knowledge-based systems development [dissertation]. Cleveland, Ohio: Case Western Reserve University; 1996.
13. Kovacic KJ. Using common-sense knowledge for computer menu planning [dissertation]. Cleveland, Ohio: Case Western Reserve University; 1995.
14. Rafidah G, Suzana S, Shahrul Azman MN, NoorAini MY. Identification of information needs for developing a computerised dietary management system among health professionals in Kuala Lumpur and Selangor. Presented at: 3rd Asian Congress of Dietetics; 2002; Kuala Lumpur.
15. Teong TS. Recommended daily dietary intakes for peninsular Malaysia. Med J Malaysia 1975 Sep;30(1):38-42. [Medline: 76100127]
16. Schofield WN. Predicting basal metabolic rate, new standards and review of previous work. Hum Nutr Clin Nutr 1985;39 Suppl 1(Suppl 1):5-41. [Medline: 86007642]
17. Cole HS, Camerini-davalos RA. Diet therapy of diabetes mellitus. Med Clin North Am 1970 Nov;54(6):1577-1587. [Medline: 71058937]
18. ; National Coordinating Committee on Food and Nutrition. Malaysian dietary guidelines. Kuala Lumpur: NCCFN; 1999.
19. Kumar K. Post implementation evaluation of computer-based information systems: current practices. Communications of the ACM 1990;33(2):203-212. [doi: 10.1145/75577.75585]
20. Saracevic T. Evaluation of evaluation in information retrieval. In: Sigir 95: 18th Annual International Acm-Sigir Conference on Research & Development in Information Retrieval. New York, NY: Association for Computing Machinery; Dec 1, 1995:138-146.
21. Keevil B. Measuring the usability index of your web site. In: Proceedings of the 16th Annual International Conference on Computer Documentation. New York, NY: Association for Computing Machinery; Sep 24, 1998:271-277.

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22.   Coiera E. The Internet's challenge to health care provision. BMJ 1996 Jan 6;312(7022):3-4 [FREE Full text] [Medline: 96135901]
23.   ; Arthur D Little Inc. Telecommunications: can it help solve America's health care problems?. Cambridge, MA: Arthur D. Little; 1992.
24.   Aadmodt A, Plaza E. Case-based reasoning: foundational issues, methodological variations and system approaches. AI Communications 1994;7(1):39-59 [FREE Full text]

Abbreviations

BMR: Basal Metabolic Rate

Original Paper

Swiss Community Pharmacies' on the Web and Pharmacists' Experiences with E-commerce: Longitudinal study and Internet-based questionnaire survey

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Abstract

Background: There are multiple ways in which community pharmacies can present themselves on the Internet, e.g., as a platform for drug information or as an advertising platform for their services.

Objective: To estimate the number of Swiss community pharmacies on the Internet over the period of 32 months (2000-2003), to describe their current e-commerce services, and to explore the experiences and plans these pharmacies have with regard to their Internet presence.

Methods: A longitudinal study was performed to determine the number of Swiss German pharmacies on the Internet by conducting Internet searches in 2000, 2001, and 2003. In April 2002, a cross-sectional Internet-based survey was administered to explore the pharmacies' experiences and plans regarding their Web sites.

Results: As of April 2003, 373 (44%) of 852 community pharmacies from the German speaking part of Switzerland were on the Internet. One hundred eighty four listed an e-mail address and were asked to complete a questionnaire. Of the 107 pharmacies answering the survey questions (58% response rate): 46% had been on the Internet for 1 to 2 years; 33% of the Web sites are part of a pharmacy group's Web portal; 31% of the pharmacies plan to expand their Internet appearance in the future; 74% provide e-commerce services, with 81% of those pharmacies filling five or less orders per month; and 12% plan on expanding their e-commerce services in the future.

Conclusions: The number of community pharmacies offering Internet services steadily increased over 32 months. Given the importance of the Internet as a tool for information, communication, and advertising for pharmacy products and services, it can be expected that the increase will continue. Pharmacy-group portals are important promoters of pharmacies on the Internet. For many community pharmacies, Internet portals that provide an Internet presence for the pharmacies and provide regularly-updated content (e.g., health news, tips, drug information) seem to be the most effective solutions. Even though 40% of the pharmacies already offer e-commerce services, these services are still of minor importance. For many pharmacists, the current legal regulations seem to be unclear. Most pharmacies want to maintain their Internet services.

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Introduction

Worldwide, more and more people are using the Internet. In 2002, 49% of the Swiss population was reported to be online

[1]. A pharmacy-specific Internet site can serve as a "Welcome Wagon", providing information about the pharmacy's hours, staff, location, and services. It can also provide a channel for patients to request information or refills, for physicians to

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prescribe, for pharmacists to assist patients with drug-related problems or to place an order with the wholesaler [2]. The Internet enables a pharmacist to communicate with patients through the use of e-mail, chat rooms, forums, videoconferencing, and other current or emerging Web communication formats [2]. Web sites created by community pharmacies could provide a quality filtered and customized information portal through which patients can access accurate, reliable drug information [2]. The Internet is the ideal tool for people to receive personalized tailored information about their disease states and medicines in the comfort of their homes and it provides more anonymity than face-to-face interactions with health care professionals, which is particularly relevant when asking embarrassing questions [3].

Given the rapidly-growing number of Web sites offering drugs on the Internet, community pharmacists are not willing to leave this new trade channel to often unidentifiable and dubious suppliers. Studies have shown that the drugs offered over the Internet are sometimes of bad quality and expensive; the origin of the drugs is often untraceable; or counseling is often unsatisfactory [4- 6]. An early paper, for example, showed that some e-pharmacies deliver drugs even if there are obvious contraindications [6]. There may be a considerable risk to patients' health. On the other hand, another study suggested that, under certain circumstances (i.e., when online services are appropriately monitored and the right drugs are chosen), online prescriptions may be no more "potentially dangerous" than, for example, self-medication with over-the-counter (OTC) drugs [7]. A number of countries have proposed or implemented regulations for Internet pharmacies, and guidelines have been prepared on the quality of drug information for the patient on the Internet [8]. Ensuring the quality of Web sites and safeguarding consumers are both complex issues [9].

In Switzerland, several ways of distributing drugs via the Internet have emerged during the last couple of years. The federal law on medicinal products and medical devices, *Heilmittelgesetz*(HMG), does not contain any special regulations regarding the Internet, but it generally prohibits mail-order trade in medicinal products [10]. The states of the Swiss confederation that have legal sovereignty in health care can issue an authorization for mail order trade, if the following conditions are fulfilled:

- the medical product (including OTC products) has been prescribed by a medical doctor
- no safety requirements stand against it
- appropriate consultation is guaranteed
- sufficient medical supervision of the effect of the medicinal product is guaranteed.

A special form of mail-order trade that does not require a special authorization is shipping drugs to regular community-pharmacy customers. A pre-existing personal relationship (face-to-face) between the pharmacy and the patient is required. Furthermore,

the service is only allowed in justified cases, e.g., if it is impossible for the patient to pick up the drug personally in the pharmacy [11]. Another option for a retail pharmacy is to affiliate with an Internet pharmacy partner (e.g., Wellshop in Switzerland [12]). The Internet-affiliation partner does not itself ship products to the patient's home but provides the necessary infrastructure (e.g., health and drug related information, 24-hour call-center) [2]. The patient either orders the desired product to be picked up in a local pharmacy or authorizes the shipment to his or her home [12].

In the view of many experts, pharmacies that combine a traditional retail operation with Internet-based business-to-consumer (B2C), so-called "bricks and clicks" pharmacies, are poised to become the most successful type of pharmacy in the future [13].

This study determines the presence of Swiss German community pharmacies on the Internet from 2000 to 2003, with special focus on e-commerce. The study addressed these questions:

- How many Swiss community pharmacies have an Internet presence?
- What are the characteristics of the community pharmacy Web sites?
- How many community pharmacies offer e-commerce services?
- What are the pharmacists' experiences and plans regarding their Internet presence?

Methods

Swiss Community Pharmacy Presence on the Internet

To determine the number of Swiss German community pharmacy Web sites, an Internet search was conducted in August 2000, with follow-up searches in December 2001, and April 2003. The Internet searches were performed with different search engines using the search term *Apotheke(pharmacy)* and two Swiss pharmacy Internet-address directories, Apo-Net and Switch. Apo-Net features a database of pharmacies maintained by Galexis, the largest drug wholesaler in Switzerland. Switch is the offical Swiss agency for the registration of Internet addresses with the top-level-domain.ch. We used their database to search for domain names containing the word "Apotheke". We used mainly Swiss search engines, to restrict the search to Swiss pharmacies. The search engines and directories used are listed in Table 1.

All hits found in the two directories were explored by clicking on each link. In addition, to complete the list, the first 200 hits found with each search engine were explored by clicking on each link. If the link turned out to be a pharmacy, name and Internet address was entered into a database. In addition, in the 2003 search, each identified Web site was checked for the presence of e-commerce services.

Table 1. Number of links found in various directories and search engines

Directory / Search engine	Number of Links Found		
	2000	2001	2003
Pharmacy Internet-Address Directories			
http://www.apo-net.ch/	64	56	117
http://www.switch.ch/	232	306	356
Search engines			
http://www.sear.ch/	3745	11470	396095
http://www.search.ch/	4637	9000	13000
http://www.google.ch/	17300	20900	27200
http://www.alltheweb.ch/	5217	6267	89163

Internet-Based Survey

An Internet-based questionnaire survey (conducted from June 2002 to July 2002) was developed to explore the pharmacists' experiences with and future plans for their Web sites. The questionnaire had 21 items and was tested in a pilot survey among 20 pharmacies. Among the 235 pharmacies that were on the Internet (according to the Internet search of 2001, 184 had provided an e-mail address. These were approached by sending an e-mail that stated the purpose of the survey and invited them to take part. The participants were given the option of completing the questionnaire online or printing the questionnaire-attached to the e-mail as a portable document format (PDF) file-and send it back by fax or by regular mail. As an incentive, the participants were promised a summary of the survey results.

Questions had preformulated responses (yes-no options, multiple-choice options) and free-text fields for adding comments. Topics addressed included: (1) general information, (2) experiences or plans for the future, (3) patients' feedback, and (4) e-commerce. The original Internet-based questionnaire is in the Appendix.

Pharmacists who did not return the questionnaire in time were sent up to 2 reminders. In the second reminder, the nonrespondents were asked to state the reason (e.g., no time or no interest in the topic) for their nonparticipation.

Data-quality assurance was conducted by randomly selecting 5% of all cases following data entry and cross-checking with the coding sheet. No miscoded data was found. No cases had to be deleted due to very unlikely or extreme values.

Data Collection and Statistics

The data (for all 3 survey parts) were collected in an anonymous manner and transferred to an Access database. SPSS (SPSS Inc, Chicago/IL, USA) was used for statistical analysis. Chi-square tests were used to test the type of Internet presence (individual Web site / part of pharmacy group's portal) and the offering of e-commerce or the duration of the Internet sites' existence and the offering of e-commerce. The a priori level of significance for type I errors (alpha) was set at <.05.

Results

Swiss Community Pharmacy Presence on the Internet

In April 2003, 44% (373/852) of the Swiss German community pharmacies had an Internet presence (Figure 1). The denominator (total number of community pharmacies) was determined from the annual report published by the Swiss Pharmaceutical Society [14]. Among the 373 pharmacies with Internet presence, 150 (40%) offered e-commerce services, e.g., reservation of products via the Internet with self pick up in the pharmacy or delivery of products ordered via the Internet only to regular pharmacy customers.

Figure 1. Number of community pharmacy Web sites: 2000, 2001, and 2003
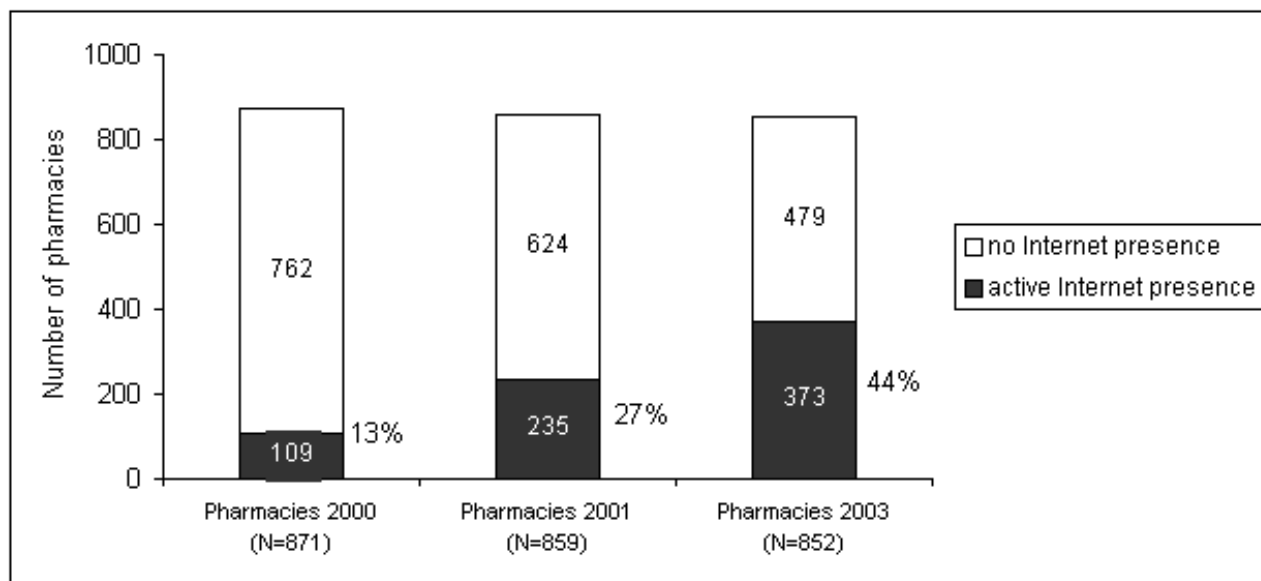
The total number of pharmacies was obtained from the annual report published by the Swiss Pharmaceutical Society [14], while the number of pharmacies with active Internet presence was determined using Internet searches as described in this paper.

Survey Results

Table 2-Table 4 show the results from the 2002 Internet-survey. Of the 184 pharmacies contacted via e-mail, 107 pharmacies answered (a 58% response rate).

Table 2. Basic characteristics of community pharmacy Web sites, as obtained through the 2002 Internet-survey.(n=107 respondents)

Characteristic	N	%
Duration of Internet presence	6	6
< 1 year	49	45
1-2 years†	45	42
2-5 years†	6	6
> 5 years	1	1
Missing response		
Type of Internet presence	71	66
Individual Web site	35	33
Part of a pharmacy group's Internet portal	1	1
Missing response		
Frequency of updates	24	22
Weekly	22	20
Monthly	3	3
Yearly	56	52
Irregularly	3	3
Missing response		
Communication with patients via e-mail	98	92
Pharmacists who receive patients' e-mails	8	8
Frequency	22	22
Weekly	68	70
Monthly		
Irregularly		

† Overlap of durations (1-2 years, 2-5 years) is an error from the questionnaire.

Table 3. Pharmacists' reasons for their Internet presence and future plans, as obtained through the 2002 Internet-survey.(n=107 respondents)

Variable	N	%
Reasons for Internet presence*	54	25
Member of a pharmacy group's Internet portal	49	22
Just to be part of the Internet	43	19
The Web site provides additional value	41	18
The Web site is a platform for independent information	27	12
The Web site is an ideal source of advertising	9	4
Other reasons		
Future plans regarding the pharmacy Web site†	67	62
Keep the Web site the same size	33	31
Expand the Web site	6	6
Downsize the Web site	1	1
Discontinue the Web site		

* N = 223 answers; allowed multiple answers.

† Based on 107 cases.

Table 4. Characteristics of the pharmacies offering e-commerce services, as obtained through the 2002 Internet-survey.(n=107 respondents)

Variable	N	%
E-commerce model*	55	37
reservation of products via Internet with self pick up in the pharmacy	37	25
affiliation with an Internet pharmacy partner	34	23
delivery of products only to regular pharmacy customers	17	12
delivery of products to all customers	4	3
other models		
Range of products†	70	39
nonpharmaceutical products (e.g., cosmetics, dietary products)	45	25
Over-the-counter (OTC) products	36	20
products from in-house production	29	16
Over-the-counter and prescription- products		
Number of orders per month‡	64	84
up to 5	8	11
5-10	4	5
10-20	-	-
> 20		
Concerns§	38	35
Regarding drug safety	51	47
no concerns	10	9
partial concerns	8	7
large concerns		
missing response		
Regarding safety of patient data:	61	56
no concerns	37	34
partial concerns	1	1
large concerns	8	7
missing response		
Knowledge of the legal situation§	38	35
total knowledge	56	52
partial knowledge	6	6
no knowledge at all	7	6
missing response		
Future of e-commerce‡	59	80
keep e-commerce services	9	12
expand e-commerce services	5	7
reduce e-commerce services	1	1
discontinue e-commerce services		

* N = 143 answers; allowed multiple answers.

† N = 180 answers; allowed multiple answers.

‡ Addressed to the pharmacies offering E-commerce (N = 79); based on 74 to 76 cases due to missing responses. Overlap of durations (up to 5, 5-10, 10-20) is in the questionnaire.

§ Addressed to all the participants (N = 107)

Basic Characteristics of the Community Pharmacy Web Sites

Basic characteristics of pharmacies online are shown in Table 2. Most pharmacies had offered Internet services for 1 to 2 years (45%) or for 2 to 5 years (42%). Sixty-two percent of the pharmacies had individual Web sites and 31% of the pharmacies had Web sites that were part of a pharmacy group's Web portal.

Fifty-two percent of the pharmacies reported that their Web sites are updated irregularly and 42% reported weekly or monthly updates; 92% of the pharmacy owners said they had been contacted by patients via e-mail.

Pharmacists' Reasons for Having an Internet Presence and Pharmacist's Future Plans

As illustrated in Table 3, 25% of the pharmacists stated they have an Internet presence because they are a member of a pharmacy group that includes all their members in an Internet portal and 22% stated they just want to be part of the Internet. Only 1 participating pharmacy plans to discontinue the Web site, while 31% of the pharmacies plan to expand their Internet presence.

As reasons for a planned expansion of the Internet site (n=31), the pharmacies stated that they want: to emphasize services in a more extensive way (34); to offer more-extensive counseling services via the Internet (e.g., provision of information regarding new drugs, health news, tips for consumers) (22); to offer e-commerce services (10); and to provide interactive communication channels (e.g., chats, forums, mailing lists) (3) (multiple answers were allowed).

As reasons for a planned downsizing (n=6) or discontinuation (n=1) of the Internet site, the pharmacies listed: financial aspects (6); expenditure of human labor (4); lack of customer feedback (4); data security (1); drug safety (1); and legal aspects (1) (multiple answers were allowed).

E-commerce

According to our survey, e-commerce services were offered by 74% of the pharmacies. Three pharmacies that are not yet offering e-commerce said that it is out of the question for them to do so in the future. The other pharmacies that are not yet offering e-commerce services either want to monitor the market (36%), want to monitor the legal situation (21%), or are planning to introduce e-commerce services within the next 12 months (11%) or by a later point of time (21%). Table 4 illustrates the characteristics of the pharmacies offering e-commerce services.

Regarding the different ways of distributing drugs via the Internet, an Internet-based reservation system (37%) or affiliation with an Internet partner (25%) are the most popular e-commerce models. There was no significant association regarding either the type of Internet presence (individual Web site / part of pharmacy group's portal) and the offering of e-commerce ($X^2_2 = 5.19$. $P > .05$), or the duration of the Internet sites' existence and the offering of e-commerce ($X^2_3 = 3.108$, $P > .05$). Regarding the range of offered products, 16% offer pharmaceutical products, while nonpharmaceutical products (e.g., cosmetics, dietary products) are the most popular with 39% of pharmacies offering those. Most pharmacies (81%) fill only 5 or less orders per month. No pharmacy fills more than 20 orders per month. The majority of pharmacists expressed at least partial concerns regarding drug safety (56%), while a minority stated at least partial concerns with regard to the safety of patient data (35%) when providing e-commerce services. As reasons for the concerns regarding drug safety, the pharmacists stated among other things: "I am afraid of misuse of drugs"; "Is the Internet-customer trustworthy?"; "A face to face conversation is missing." Regarding concerns about the safety of patient data, the pharmacists stated: "Specific security systems (e.g., firewalls) are missing"; "Pharmacists don't have enough computer knowledge"; "There is a fear that submitted customer information could be seen by others." Thirty-eight percent of the participants stated they have total knowledge of the legal situatio n regarding e-commerce with drugs in Switzerland. Most pharmacies plan to keep (80%) or expand (12%) e-commerce services in the future, one pharmacy wants to withdraw from e-commerce services.

Discussion

Internet Presence

This study revealed that the number of pharmacies with an Internet presence doubled (109 in 2000; 235 in 2001) within the first 16 months and increased by another 59% (373 in 2003) within the second 16 months. A further increase can be expected, as there are still 479 community pharmacies (April 2003) that do not yet have an active presence on the Internet. In a recently-conducted survey (2001) with Swiss pharmacists, 41% stated they would like to be on the Internet with a Web site and 88% already had access to the Internet in the pharmacy [15]. As the results from this present study show, there are already more than those 41% with an Internet presence (44% in 2003). Regarding small- and medium-sized businesses in Switzerland, 33% were on the Internet in 2000 [16]. In 2001, 11% of the community pharmacies in Germany were on the Internet [17]. The importance of community pharmacy Web sites could gain importance in the future as, e.g., in the United States already 22% of the patients choose health care professionals based on information they find on the Internet [18].

One third of the pharmacies' Internet sites are part of a pharmacy-group's Internet portal. The pharmacy-groups' Internet portals (60% of the Swiss community pharmacies belong to chain or group organizations [19]) are a way for single pharmacies to become integrated into an Internet portal that is regularly updated by health care professionals and provides patients with up-to-date content (e.g., health news, tips, drug information).

Plans/Reasons for Being on the Internet

As a recent Swiss patient survey revealed, 55% of patients do not feel the need for a community pharmacy Web site [20]. But this situation is likely to change. According a report by Striegler, community pharmacies without Web sites will lose a lot of customers [21]. More and more patients are likely to select pharmacies based on information they find on the Internet (e.g., on services pharmacies offer, such as diagnostics). Only a minority of the pharmacists plan on downsizing or giving up their Internet site in the future. Most of them seem to realize the importance of having a presence on the Internet, but only one-third plan to expand.

So far, only 19% of the pharmacists see their Web site as an additional value and only 18% as a platform for independent information, to become a drug-information center as proposed by experts in a recent survey [20,22]. One pharmacist's statement, that through the Internet "he wants to open the door to young customers," is a very important argument. Young people grow up with the Internet and its applications. A study by the Swiss Federal Office for Statistics described the typical Swiss Internet user as being young, male, and educated [1].

E-commerce

In the summer of 2002, 74% of the Swiss pharmacies that were on the Internet provided e-commerce services. In Germany, this figure amounted to 32% in 2001 [17].

Seventy-two percent of the pharmacies that offer e-commerce services in Switzerland are affiliated with the Swiss Internet pharmacy partner Wellshop [12]. Of the 7500 monthly visitors to the Wellshop platform, only 1% used it to purchase OTC drugs online in 2001. Wellshop is currently mainly used as a drug-information platform [23]. A recent survey (2002) among Swiss pharmacy clients revealed that 2% of the Internet users have purchased drugs online [24]. Even though the number of online orders filled by the participating Swiss pharmacies is still very low, 80% would like to keep e-commerce services in the future and 12% would even like to expand their e-commerce services. The interest in e-commerce for drugs could increase in the future as 31% of the Swiss Internet users would be willing to order drugs online in the future [24].

Because relatively little information was known about the nonresponders, it could not be ruled out that pharmacies offering e-commerce services were overrepresented among the respondents. Regarding this possible bias, the pharmacy Web sites were checked for the presence of e-commerce services during the search of April 2003. The fact that in 2003 a total of 40% of the Web sites offered e-commerce services confirmed the assumption that the respondents of the 2002 survey might not be representative regarding the provision of e-commerce services (according to the 2002 survey, e-commerce services were offered by 74% of the pharmacies).

According to a British study, the 4 main groups buying pharmaceutical products online are: busy executives, mothers at home, the elderly or disabled, and those making embarrassing purchases [24]. The main reasons for buying drugs online are convenience and privacy [24,25].

Our finding that many pharmacists have only partial or no knowledge of the legal situation regarding e-commerce with drugs in Switzerland was confirmed by an investigation in 2003 [26]. It revealed that 34% of the pharmacies that are affiliated with Wellshop [12] do not require a prescription for ordering OTC-drugs even though, as stated in the federal law on medicinal products and medical devices (Heilmittelgesetz [10]), a prerequisite for mail order trade in medicinal products is a prescription by a medical doctor. It is important for community pharmacies to strictly respect the legal situation and apply the same level of quality they do when dispensing drugs in the traditional way. As explained in the "Introduction" for mail order, a prescription is needed for all kinds of drugs, including OTC drugs, which normally do not require a prescription.

Limitations of the Survey

Relatively little information is known regarding the Internet-based survey nonrespondents. Only a minority of them stated the reason for not taking part in the survey. It cannot be ruled out that those who took part in the survey are more Internet savvy and are utilizing their Internet site in a more extensive way, e.g., regarding e-commerce. Furthermore, this study only measures the situation in Switzerland from 2000 to 2003. Considering the dynamic development in Internet presence and drug distribution over the Internet, this study would have to be repeated on a regular basis.

Conclusions

The number of community pharmacies offering Internet services steadily increased over the 32 months covered by the survey. Because of the importance of this new medium as a tool for information, communication, and advertising for pharmacy products and services, the increase can be expected to continue. Pharmacy-group portals are important promoters of pharmacies on the Internet. For many community pharmacies, Internet portals that provide an Internet presence for the pharmacies and provide regularly-updated content seem to be the most effective solution. Even though 40% of the pharmacies already offer e-commerce services, it is still of minor importance. For many pharmacists, the current legal regulations seem to be unclear. Most pharmacies want to maintain their Internet services.

Conflicts of Interest

Documed AG publishes the official Swiss drug reference book (Arzneimittelkompendium) and other publications in the field of drug information in print as well as in electronic form and is active in the field of eHealth. Documed AG gave input at the beginning of the studies and their interests lie in the number of pharmacies with an Internet presence and in e-commerce services offered.

Multimedia Appendix

Original Internet-Based Questionnaire

Questionnaire "Pharmacies on the Internet: Survey concerning past experiences and future plans": [HTML File, 60KB - jmir_v6i1e9_app1.html]

References

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1.   ; Bundesamt für Statistik. Informationsgesellschaft Schweiz. URL: http://www.statistik.admin.ch/stat_ch/ber20/publ/dpub01-01.htm [accessed 2002 Nov 15]

2.   Felkey B. Threats and opportunities of the Internet for pharmacy practice. Int Pharm J 2000;14(1):11-13. [doi: 10.1097/00124363-200002000-00007]

3.   Anderson C. The Internet and its implication for pharmacy. Int Pharm J 2001;15:17-19.

4.   Rupf R. Medikamente über Internet. Schweiz Apoth Ztg 2000;138:4-7.

5.   ; Swissmedic. Gesundheitsrisiko: E-commerce mit nicht zugelassenen Präparaten. Schweiz Apoth Ztg 2002;140:342.

6.   Eysenbach G. Online prescribing of sildanefil (Viagra) on the world wide web. J Med Internet Res 1999 Dec 31;1(2):e10 [FREE Full text] [Medline: 21577984] [doi: 10.2196/jmir.1.2.e10]

7.   Jones MJ. Internet-based prescription of sildenafil: a 2104-patient series. J Med Internet Res 2001 Jan 31;3(1):e2 [FREE Full text] [Medline: 21578009]

8.   Van Mil F. Pharmacy and the Internet, an overview. Int Pharm J 2000;14(1):6. [doi: 10.1097/00124363-200002000-00004]

9.   Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Quality of global e-pharmacies: can we safeguard consumers? Eur J Clin Pharmacol 2002 Dec;58(9):567-572. [doi: 10.1007/s00228-002-0519-5] [Medline: 22370712]

10. Bundesversammlung der Schweizerischen Eidgenossenschaft: Bundesgesetz über Arzneimittel und Medizinprodukte (Heilmittelgesetz, HMG); Dec 2000. (Stand am 20. Januar 2004) URL: http://www.admin.ch/ch/d/sr/8/812.21.de.pdf [accessed 2001 Jan 15]

11. ; Arbeitsgruppe E-Commerce. E-commerce mit Arzneimitteln. URL: http://www.swissmedic.ch/files/pdf/Schlussbericht_e-commerce.pdf [accessed 2001 Sept 27]

12. ; Documed AG. Wellshop. URL: http://www.wellshop.ch/ [accessed 2001 May 1]

13. Muehlemann H. Zustände wie in Amerika. OTC World 2002;6(37):1-4.

14. ; Schweizerischer Apothekerverband. Apotheken in der Schweiz 2000-2003. Jahresbericht SAV 2003;15:68-70.

15. Zehnder S, Beutler M, Bruppacher R, Ehrenhöfer T, Hersberger K. The needs and use of drug information sources in German speaking community pharmacies: a questionnaire based survey. Pharm World Sci [in press].

16. Degen O. Die Informationstechnologien erobern die Wirtschaft. Basler Zeitung: Beilage der BAZ vom Samstag / Sonntag; 2002 Jan 5.

17. Jopp R. Die öffentliche Apotheke im Internet. Dtsch Apoth Ztg 2001;141(25):87-91.

18. Hill S. "Internet-challenge" im Gesundheitswesen. (Zitat). URL: http://www.nzz.ch/ [accessed 2001 April 9]

19. von Arx J, Schlips B. Rollende Kostenstudie in der Apotheke (RoKA2001). Schweiz Apoth Ztg 2002;140:708-712.

20. Zehnder S, Hersberger K, Beutler M, Bruppacher R. Resultate einer Apotheken- und Expertenbefragung - Arzneimittelinformationen für Apotheken. Schweiz Apoth Ztg 2001;139:858-860.

21. Striegler A. Die Apotheke im Internet. Pharm Ztg 2000;145(16).

22. Zehnder S, Hersberger K, Beutler M, Bruppacher R. Was denken Experten? Schweiz Apoth Ztg 2001;139(11):372-374.

23. ; OTC World. Wer hat Angst vor dem Internet? OTC World 2002;34:1-5.

24. Zehnder S, Beutler M, Bruppacher R, Hersberger K. Drug information sources used by patients in Switzerland: an in-pharmacy-survey on the use of drug information sources with special focus on new information technologies. J Soc Adm Pharm 2003;20(5):156-165.

25. Curphey P. The implications of e-commerce for community pharmacy. Pharm J 2000;265:580 [FREE Full text]

26. Bröhm A. Illegaler Online-Handel. Sonntagszeitung 2003 Mar 23;Sect. Online:124.

Abbreviations

OTC: Over-the-counter (non-prescription)

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