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Original Paper

Effective and Safe Management of Oral Anticoagulation Therapy in Patients Who Use the Internet-Accessed Telecontrol Tool SintromacWeb

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Abstract

Background: Despite the existing evidence that highlights the benefits of oral anticoagulation therapy (OAT) self-testing and self-management by patients in comparison with conventional control, significant progress is still needed in the implementation of computer-based, Internet-assisted systems for OAT within health care centers. The telecontrol tool “SintromacWeb” is a previously validated system for OAT management at home, which is currently operative and accessed by patients through a hospital Web portal.

Objective: The intent of the study was to assess the effectiveness and safety of OAT management in patients using the SintromacWeb telecontrol system in reference to control in patients using the conventional system (management at the hematology department), in terms of time in therapeutic range (TTR) of International Normalized Ratio (INR).

Methods: In this observational prospective study, patients were identified by their physician and divided in two groups according to the OAT management system that they were already using (conventional control or telecontrol with SintromacWeb). For 6 months, patients were required to visit the hematology department every time their physician considered it necessary according to usual clinical practice. Sociodemographic and clinical variables for the study were collected at first visit (baseline) and at those visits closest to 2, 4, and 6 months after first visit.

Results: A total of 173 patients were evaluated, 87 with conventional control and 86 with telecontrol. Follow-up time was a median of 6.3 (range 5.2-8.1) months. The average time of OAT treatment prior to enrollment was 9.2 (SD 6.4) years. Patients in the telecontrol group tested their INR a median of 21 (range 4-22) days versus a median of 35 (range 14-45) days in patients in the conventional control group ($P<.001$). TTR in the telecontrol group was 107 (SD 37) days versus 94 (SD 37) days in the conventional control group (an increase of 12.6%; $P=.02$). In all visits, the percentage of TTR was higher in the telecontrol group (at the third visit: 59% vs 48%; $P=.01$). Higher TTR (positive coefficient) was associated with patients under OAT telecontrol ($P=.03$). Under-anticoagulation (INR<1.5) and over-anticoagulation (INR>5) were observed in 34 (19.7%, 34/173) and 38 (22.0%, 38/173) patients, respectively (no differences between treatment groups). Seven thrombotic and/or bleeding events were serious, 12 were non-serious, and most of them (5 and 10, respectively) occurred in the conventional control group.

Conclusions: In clinical practice, OAT management with the Internet-based tool SintromacWeb is effective and safe for those patients who are eligible for OAT telecontrol.

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KEYWORDS

oral anticoagulant therapy; International Normalized Ratio; Internet; self-management software; telecontrol; SintromacWeb

Introduction

Oral anticoagulation therapy (OAT) with vitamin K antagonists effectively reduces the risk of thromboembolism in patients with hereditary or acquired thrombophilia, heart valve replacement, atrial fibrillation, and other conditions [1]. Studies carried out in Spain and Italy showed a prevalence for OAT of 1.32% and 0.81%, respectively, with atrial fibrillation as the main cause of an indication for anticoagulation therapy (47.1% and 45.6%, respectively) [2,3].

The INR (International Normalized Ratio) is a standardized number obtained by means of a laboratory test that determines the degree of anticoagulation level achieved by the vitamin K antagonist [4]. The goals of OAT are both preventing thromboembolism and minimizing the risk of bleeding complications by reaching and maintaining the INR within the appropriate range for each patient, depending on their disease [5]. To summarize the INR control over time, percent time in therapeutic range (TTR) of INR is used.

Monitoring of OAT patients is conventionally carried out in hospitals and primary care centers, which are in contact with the referring hematologist in specialized hospitals. However, there is extensive literature that supports effectiveness and safety of OAT self-management by patients at home and shows that self-management at home is similar or even more effective and safer than in conventional control [6-9]. Decentralized management not only lightens the burden in health centers, but also prompts fewer monitoring visits to specialized centers, resulting in more freedom for the patient and improved quality of life [10-12]. Furthermore, that the patient is provided with greater responsibility in measuring and dosing their own INR can increase awareness, commitment, and interest in the management of their disease.

According to biomedical literature, any new management model should demonstrate anticoagulation control levels over 60% for TTR of INR to be considered safe and be within at least 5 to 10% compared with routine monitoring to declare it as a better model [6-8]. Since TTR is a parameter strongly associated with the occurrence of clinical events, its use as a primary endpoint in clinical trials of anticoagulation is recommended [13]. Few randomized trials assessing TTR-based effectiveness and/or safety of OAT self-testing programs have been performed so far [14-20]. Importantly, no trial has tested a validated, already implemented system in a hospital for OAT telecontrol at home.

“SintromacWeb” is a new-generation, Internet-based system developed by Grifols (Barcelona, Spain) as an alternative tool to conventional OAT management. SintromacWeb has already been successfully tested and validated in terms of reliability, consistency, and patient satisfaction [21]. The system is currently operative in the *La Fe* University Hospital (Valencia, Spain), and it is accessed by patients through the hospital Web portal.

Designed as the natural extension of its predecessor [21], this study prospectively assessed both effectiveness, in terms of TTR, and safety of OAT management in patients using the SintromacWeb system in clinical practice, compared to patients

using management at the hematology department, a system considered conventional.

Methods

Study Design and Objectives

This prospective, observational study was conducted at the *La Fe* University Hospital in Valencia, Spain. The study was performed in accordance with the Declaration of Helsinki and approved by the Ethics Committee for Clinical Investigation by the *La Fe* Hospital.

The main objective of this study was to assess the effectiveness and safety of OAT management in patients using the SintromacWeb compared to OAT management in patients using the conventional control (management at the hematology department). Therefore, the TTR of the INR in both groups were compared.

Secondary objectives were to assess the percentage of patients with INR within the therapeutic range at the time of each visit, the proportion of INR values within and outside of the therapeutic range, and the extreme values indicative of under-anticoagulation (INR<1.5) or over-anticoagulation (INR>5.0).

The safety objective was to assess the presence of abnormal coagulation events such as the number and severity of thromboembolism and bleeding events during the follow-up period.

SintromacWeb System Description

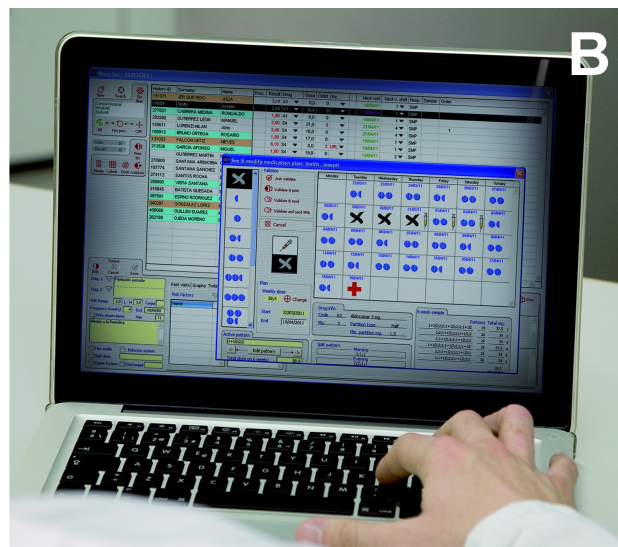
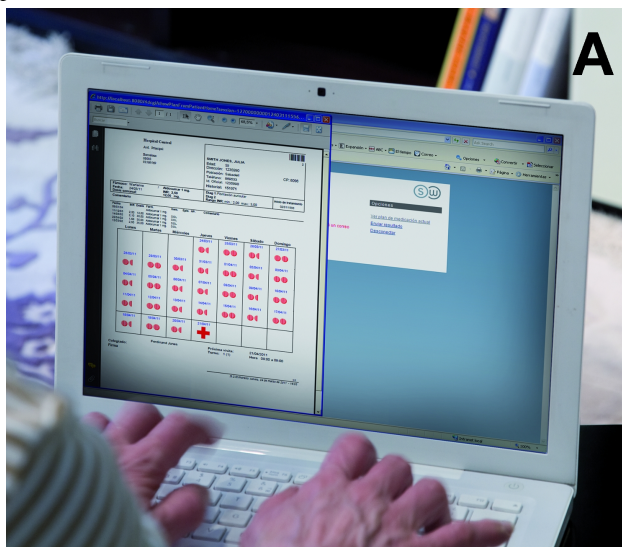
The SintromacWeb system for OAT telecontrol at home consists of two key elements: a point-of-care (POC) device for patients' INR self-testing and software that allows online interaction with physicians.

The POC device used was the HemoSense INRatio (Philips Remote Cardiac Services, Windsor CT), which is a monitoring system for INR home testing. The INRatio is capable of receiving the prothrombin time and INR results in less than a minute by using a small blood drop. A test strip is inserted into the INRatio monitor and a sample of fresh whole blood (15 µL) received from a finger prick is applied to the test strip. Blood is drawn into the test area by capillary action where it mixes with coagulation inducing reagents. The monitor performs the test and determines whether the controls are within pre-set limits.

The SintromacWeb software allows OAT patients to communicate with their doctors online, at home, or wherever an Internet access point is available. The SintromacWeb site is hosted by the same server as the *La Fe* Hospital website and is accessed through the hospital portal. Patients are provided with a username and password, which allows them to enter their personal area (Figure 1 A). The current medication schedule can be viewed, and according to the self-testing program, INR results are introduced and sent to the health care center. As a result, the hematologist can connect to the system, analyze the data, and introduce a new medication schedule for the patient (Figure 1 B). After the doctor has updated the schedule, an email is sent to the patient informing them that the treatment

recommendations are available in their personal area of SintromacWeb.

Figure 1. Illustrative pictures of the SintromacWeb software. In patient's personal area (panel A), current medication schedule is available; INR results are introduced and sent to health care center. In physician's area (panel B), the hematologist analyzes the data and introduces new medication schedule for patient.



Patients and Recruitment

All patients were enrolled at the Hemostasis and Thrombosis Unit of the Hematology Service of the *La Fe* Hospital. The enrollment period lasted 3 months and patients were followed for 6 months.

The main inclusion criteria were: patients aged 18 years or older, under OAT treatment (either telecontrol or conventional control) for at least 3 months before inclusion in the study, and expected to be under OAT for at least 6 months after the inclusion in the study. The main exclusion criteria included patients who did not follow criteria for treatment adherence according to the investigator, patients who were not able to follow the visit schedule, and patients participating in another clinical trial during the study period.

Patients who met the criteria were identified by their physician when they came to the hematology department for a routine visit. Candidates were invited to participate in the study, and after acceptance, written informed consent was obtained. Patients were divided in two groups according to the OAT management that they were already following (conventional control or telecontrol with SintromacWeb). Patients using the telecontrol management system came from the cohort of the previous study in which the main inclusion criteria were patients aged 18 years or older with adequate technical facilities at home (computer and connection to the Internet) to run the Web-based telecontrol tool [21]. Recruitment ceased when the calculated minimal population size for each treatment group was reached.

Variables of the Study

During the follow-up period, patients were required to visit the hematology department for OAT every time their physician considered it necessary, according to usual clinical practice. Variables of interest for the study were collected at four time points according to the following schedule: first visit (baseline) at the beginning of the study and at three follow-up visits (those

closest to 2, 4, and 6 months after first visit). Variables corresponding to the 3 months prior to the first visit were obtained from the patient's clinical records.

Information was gathered in a Case Report Form (CRF) specifically designed for the study. Confidentiality of the patient's identity was preserved according to Spanish law for personal data protection.

Clinical data related to the study included starting date of OAT, indication for OAT, frequency scheduled by the physician for INR measurement, and target INR range and its changes during the follow-up period.

At the three follow-up visits, INR measurements and adverse events were collected. Adverse events included the presence of thromboembolism and its seriousness (major: deep thrombosis or non-transient ischemia; minor: surface thrombosis or transient ischemia) as well as the presence of bleeding/hemorrhage and its seriousness (major: fatal and/or symptomatic bleeding into a critical area or organ, and/or bleeding that causes a decrease in hemoglobin ≥ 20 g/L, or which requires the transfusion of two or more units of whole blood or red blood cells, and/or gastrointestinal, urogenital, hemoptysis; minor: other not included in the described concepts).

Time in Therapeutic Range (TTR) Assessments

For the purpose of this study, two therapeutic INR target ranges were defined: (1) INR 2-3 for OAT indications of deep vein thrombosis/pulmonary embolism, atrial fibrillation, heart valve disease, and heart valve bioprosthesis, and (2) INR 2.5-3.5 for indications of mechanical prosthetic heart valve, and venous thrombosis or stroke repetition in the context of antiphospholipid syndrome [22,23].

The primary endpoint of the study, TTR, was calculated using the approach proposed by Rosendaal [4], in which it is assumed that the INR value between two consecutive determinations varies linearly and the value of INR estimated for each of the

days between consecutive measurements at intervals of increase/decrease of INR is ≥ 0.1 . The Rosendaal method INR-specific for person-time takes into account the frequency of INR determinations and their actual values. By considering the individual values of INR collected at each visit with respect to the previous visit and the time elapsed between the two determinations, the TTR was calculated as the percentage of days within the therapeutic range out of the total days of treatment.

Statistical Analysis

Population sample size was calculated by taking into consideration that the estimated average TTR is approximately 65% with a standard deviation (SD) of 20. Calculations showed that 174 patients (87 patients in each group) were needed to detect a difference of 8.5% in TTR between the two groups of OAT control (to meet the 5-10% difference between methods as recommended in the literature [6-8]) with a power of 80% and a significance value of $P=0.05$. The analysis was stratified according to the type of OAT management to allow for the comparison between groups.

Continuous variables are presented as the mean (SD) or as median and range (minimum-maximum). For categorical variables, the number and percentage by category are used. For continuous variables, study groups were compared using Student's *t* test. In case of different baseline characteristics between groups, comparison was made by adjusting variables

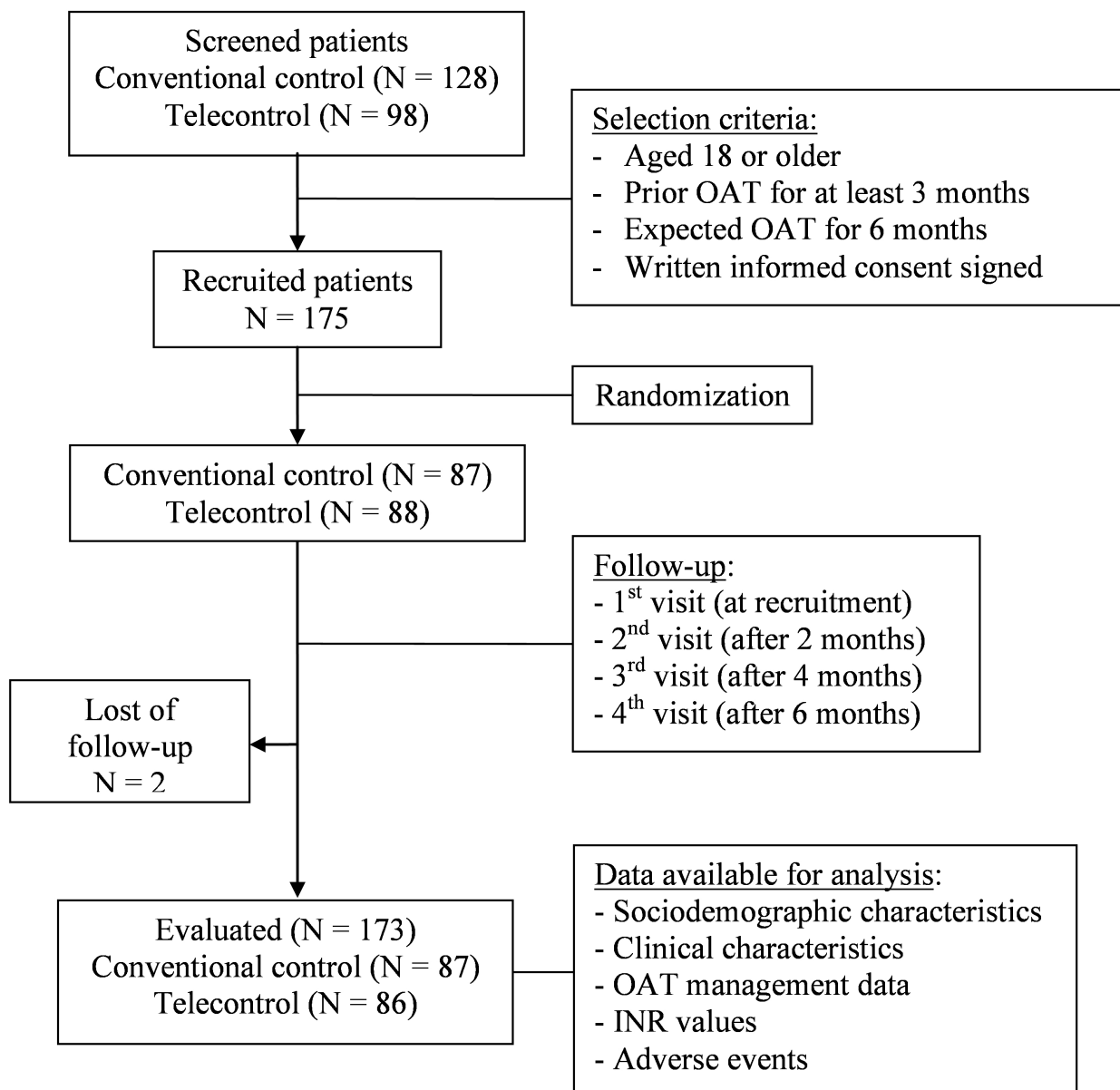
using a linear regression model. For categorical variables, comparison between study groups was performed using the chi-square or Fisher's test when the expected values of at least 80% of the cells in a contingency table were >5 .

In all cases, statistical significance level was set at $P \leq 0.05$. The statistical package SAS v. 9.2 for Microsoft Windows was used for calculations.

Results

A total of 175 patients who met the inclusion criteria were enrolled in the study (88 in the conventional OAT control group and 87 in the telecontrol group). Two patients died before 3 months of follow-up: one in the conventional control group (an 84-year old female with obesity, diabetes, dyslipidemia, hypertension, and heart failure; death after aortic valve prosthesis implant) and one in the telecontrol group (a 57-year old male with obesity, dyslipidemia, hypothyroidism, heart failure, smoking habit, and chronic obstructive pulmonary disease; death from sudden cardiac arrest with anoxic encephalopathy).

At the end of the study, 173 patients were evaluated: 87 in the conventional control group and 86 in the telecontrol group. Follow-up time was a median of 6.3 (range 5.2-8.1) months with 6.4 (range 5.7-8.1) months in the conventional control group and 6.2 (range 5.2-7.1) months in the telecontrol group. [Figure 2](#) shows the flow of patients through the study.

Figure 2. Flow of patients through the study.

Population Characteristics

The mean age of patients was 64.0 (SD 14.1) years (range 18-93) with 53.2% (92/173) of patients between 50 and 70 years. Patients were 50.3% (87/173) male and 95.4% (165/173) Caucasian. Most patients had a high school, college, or university education (58.4%, 101/173). Retirement was the most common labor status (50.6%, 87/172), while living accompanied (partner and/or with family: 86.7%, 150/173) was the most common family environment. Details of the sociocultural and environmental profile of patients in the two treatment groups are summarized in [Table 1](#). Variables in both treatment groups were balanced with the exception of sex (more males in the

telecontrol group) and family environment (more patients living alone in the conventional control group).

Most patients (97.7%, 169/173) presented comorbidities during the study. The most prevalent concomitant diseases were arterial hypertension (73.4%, 127/173), dyslipidemia (63.0%, 109/173), cardiovascular diseases (48.0%, 83/173), heart failure (34.1%, 59/173), obesity (34.1%, 59/173), diabetes mellitus (24.3%, 42/173), ischemic stroke (17.9%, 31/173), and chronic obstructive pulmonary disease (11.6%, 20/173). Hemorrhagic stroke, malignancy, inflammatory bowel disease, and nephritic syndrome were also present and had a prevalence <10%. Percentages of concomitant diseases were similar between the two treatment groups.

Table 1. Demographic, socio-cultural, and environmental profile of patients in the two oral anticoagulant therapy (OAT) management study groups: conventional control and telecontrol with the SintromacWeb system.

Variable	OAT management	
	Conventional (n=87) mean (SD) or n (%)	Telecontrol (n=86)
Demography		
Age, years, mean (SD)	65.0 (13.9)	62.9 (14.5)
Body mass index, kg/m ² , mean (SD)	27.4 (5.8)	27.5 (5.0)
Male, n (%)	33 (38)	54 (63) ^a
Caucasian, n (%)	83 (95)	82 (95)
Educational level, n (%)		
No schooling	11 (13)	3 (4)
Primary	32 (37)	26 (30)
High School	20 (23)	24 (28)
College / University	24 (28)	33 (38)
Working status, n (%)		
Active worker	19 (22)	27 (31)
Retired	45 (52)	42 (49)
Housewife	14 (16)	8 (9)
Temporary disability	2 (2)	2 (2)
Unemployed	2 (2)	4 (5)
Student	1 (1)	2 (2)
Other	3 (4)	1 (1)
Family environment, n (%)		
Living alone	17 (20)	4 (5) ^b
Living with partner	49 (56)	55 (64)
Living with relatives	20 (23)	25 (29)
Other	1 (1)	2 (2)

^a*P*=.001^b*P*=.04

OAT Management Data

The most common OAT-requiring pathologies presented by patients were atrial fibrillation (65.3%, 113/173), cardiac valve prosthesis (38.7%, 67/173), and cardiac valvulopathy (37.6%, 65/173), while coronary artery disease, stroke, and deep vein thrombosis were presented by in around 15-20% of patients. Details of the OAT-requiring pathologies in the two treatment groups are summarized in [Table 2](#).

The average time of OAT treatment prior to enrollment in the study was 9.2 (SD 6.4) years (8.1 years in the conventional control group and 10.2 years in the telecontrol group). Most patients were in the range of 5 to <10 years of treatment (31%, 27/87 in the conventional control group and 42%, 36/86 in the

telecontrol group), followed by the range of 10 to <20 years (20%, 17/87 in the conventional control group and 33%, 28/86 in the telecontrol group), and the range of 1 to 5 years (31%, 27/87 in the conventional control group and 15%, 13/86 in the telecontrol group). A total of 14.4%, 25/173 of patients were <1 year or ≥20 years in treatment.

Median frequency of INR testing was higher in the telecontrol group (every 21 days; range 4-22) than in the conventional control group (every 35 days; range 14-45) (*P*<.001). The target INR ranges were virtually the same in both OAT groups: INR 2-3 in 56% and 57% (49/87 and 49/86, respectively) of patients and INR 2.5-3.5 in 44% and 43% (38/87 and 37/86, respectively) of patients. The INR target ranges did not change during the follow-up period.

Table 2. Oral anticoagulant therapy (OAT)-requiring pathologies of patients in the two study groups (conventional control and telecontrol with the SintromacWeb system).

Pathology	OAT management	
	Conventional (n=87) n (%)	Telecontrol (n=86)
Atrial fibrillation	61 (70)	52 (61)
Cardiac valve prosthesis	34 (39)	33 (38)
Cardiac valvulopathy	36 (41)	29 (34)
Stroke of cardiac origin	20 (23)	16 (19)
Coronary artery disease	19 (22)	17 (20)
Deep venous thrombosis	13 (15)	13 (15)
Venous/arterial thromboembolism	10 (12)	11 (13)
Prevention of recurrent thromboembolism	10 (12)	11 (13)
Recurrent venous thrombosis	8 (9)	10 (12)
Myocardiopathy	5 (6)	9 (11)
Pulmonary thromboembolism	3 (3)	5 (6)
Other causes	35 (40)	36 (42)

OAT Control Effectiveness

The mean TTR of INR—the primary endpoint of the study—was 8% higher (95% CI: 1.82-13.86) in the telecontrol group than in the conventional control group (62%, SD 21% vs 54%, SD 19%, respectively; $P=.01$). This difference represents a relative increase of 12.6%. The distribution of patients according to ranges of TTR is shown in Table 3. In absolute terms, TTR in the telecontrol group was 107 (SD 37) days while in the conventional control group TTR was 94 (SD 37) days ($P=.02$).

According to visits, TTR in the telecontrol group was always higher than in the conventional control group—the maximal

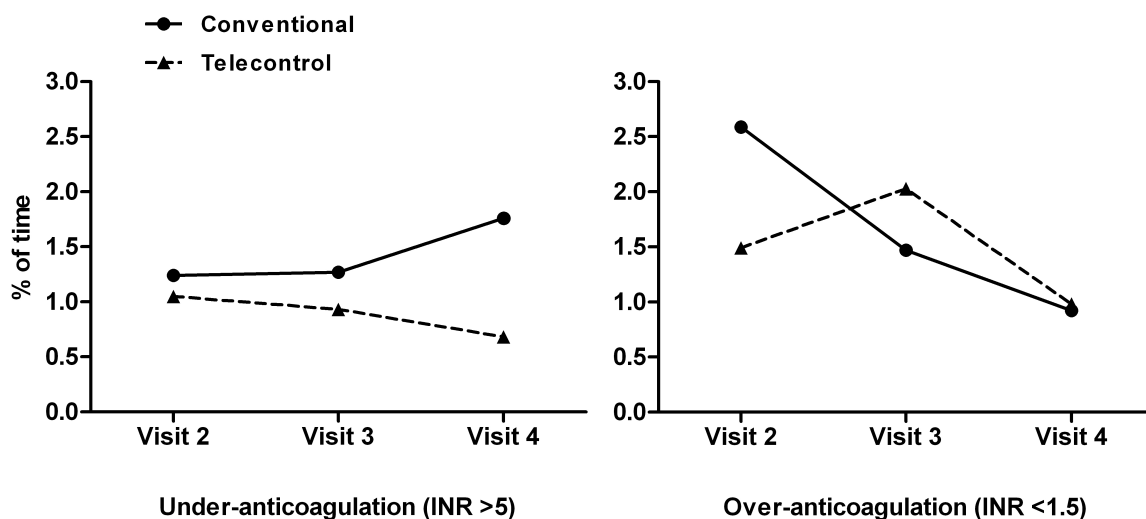
difference being observed at the third visit (59% vs. 48%, respectively; $P=.01$).

The average minimum and maximum INR values were 1.8 (SD 0.4) and 4.2 (SD 1.1), respectively. Only 19.7% (34/173) patients showed under-anticoagulation (INR<1.5) at some visit while over-anticoagulation (INR>5) was present in 22.0% (38/173) patients. Values were similar in the two OAT management groups. Figure 3 illustrates the evolution of the percentage of time in under- and over-anticoagulation during the 6-month follow-up. The mean percentage of time in which INR was <1.5 or >5 was 1.1% (SD 3.4%) and 1.4% (SD 3.6%), respectively.

Table 3. Distribution of patients of the two oral anticoagulant therapy (OAT) treatment groups (conventional control and telecontrol with the SintromacWeb system) according to ranges of percentage of time in therapeutic range (TTR) during the follow-up period.

TTR	OAT management	
	Conventional (n=87) n (%)	Telecontrol (n=86)
<30%	9 (10)	8 (9)
30% – <50%	29 (33)	16 (19)
50% – <70%	31 (36)	29 (34)
≥70%	18 (21)	33 (38)

Figure 3. Evolution of average time in under- and over-anticoagulation (International Normalized Ratio [INR] <1.5 and INR>5, respectively) in the 3 visits of the follow-up period. The two oral anticoagulant therapy (OAT) management groups (conventional control and telecontrol with SintromacWeb system) are shown.



OAT Control Safety

A total of 19 thrombotic and/or bleeding events during the follow-up period occurred in 13% (11/87) patients of the conventional control group, but only in 4% (3/86) patients of the telecontrol group ($P=0.03$). The distribution of the events according to seriousness is shown in Table 4. Globally, 7 events were serious, 12 were non-serious, and most of them (5 and 10, respectively) occurred in the conventional control group.

The most common thrombotic event was transient ischemic attack (2 episodes), while there were single episodes of pulmonary thromboembolism, deep vein thrombosis, superficial venous thrombosis, and ischemic heart disease. Conversely, unspecified minor bleeding (9 episodes) and unspecified major bleeding (2 episodes) were the most common bleeding/hemorrhagic events. There was also one episode of gastrointestinal bleeding and one episode of urogenital bleeding.

Table 4. Distribution of thrombotic and bleeding events in the two groups of oral anticoagulant therapy (OAT) management groups (conventional control and telecontrol with the SintromacWeb system), according to seriousness.

Adverse events	OAT management	
	Conventional	Telecontrol
Serious		
Thrombotic	3	0
Bleeding	2	2
Total serious	5	2
Non-serious		
Thrombotic	2	1
Bleeding	8	1
Total non-serious	10	2
Total adverse events	15	4

Discussion

Principal Findings

Vitamin K antagonists are still the anticoagulant of choice for many patients, even in the face of the pharmacologic advantages shown by new oral anticoagulants targeting either thrombin or factor Xa. The higher drug cost of new oral anticoagulants often restricts their use to patients with risk of failure to maintain the INR in the therapeutic range (eg, with atrial fibrillation at risk

for stroke). In addition, vitamin K antagonists are preferred for patients with uncertainties for dosing, such as those with renal dysfunction and those in marked extremes of body weight [24]. Therefore, the development of OAT self-testing and self-management systems to improve patient’s quality of life is warranted [6-9,14-20,25-27]. However, widespread implementation of computer-based, Internet-assisted systems within health care centers has not happened. This is the first study in which a previously described, validated, fully operative and currently in use telecontrol system in a hospital for OAT

management at home (SintromacWeb) has been assessed in a prospective trial. Our results indicate that OAT management with the SintromacWeb is effective and safe in terms of clinical practice.

The observational nature of this study can be considered a limitation when interpreting the results. Investigators did not modify their usual clinical practice. In addition, since patients in the telecontrol group were recruited under defined clinical criteria as described in the previous study [21], some differences between the treatment groups were not unexpected. Two patient demographic variables were dissimilar between groups: the proportion of male/female and the proportion of patients living alone/accompanied. This is possibly linked to the fact that patients using the telecontrol tool were required to have a computer and a connection to the Internet at home [21]. The aim of the study was not to determine which OAT management system was superior, but to determine whether the telecontrol system is effective and safe in those patients who are able to use it based on clinical criteria in reference to patients using the conventional system, regardless of the patient profile in each group. In addition, the analysis was stratified to allow the comparison between groups.

Overall, the primary characteristics of the patients in our study were typical as a target of OAT treatment and within the clinic population values and ranges shown by other trials, such as mean age (64 years; range 57-75 in other trials) and percentage of males (50%; range 43-72% in other trials) [8,14-20]. The follow-up period of 6 months is also similar to most of those trials.

Patients in the telecontrol group achieved a relative 12.6% greater TTR value than patients in the conventional control group. Moreover, longer TTR in the telecontrol patients was consistently observed in all the scheduled visits during the study follow-up. Therefore, patients using the telecontrol system can be considered to have a good control of their OAT management. In some randomized trials, INR self-testing has been reported to be as good as [14,16,26] or better [8,15,17-20,25,27] than conventional testing. In particular, in a study performed with an Internet-based system for the supervised remote management

of patients on OAT, Ryan et al indicated a TTR improvement of 15.4% in patients on INR self-testing [8]. However, since our study was observational, any comparison must be viewed with caution.

In our study, the frequency of INR measurements was higher in patients of the telecontrol group than in patients of the conventional control group (around 3 weeks vs 5 weeks, respectively). Although there is no consensus between the major guidelines on the optimal frequency of INR testing to achieve good INR control, it has been described that self-testing patients have increased frequency of INR measurements [28,29], which can be related to an improvement of the clinical outcomes of OAT.

In contrast with another trial [8], our study showed that both under-anticoagulation (INR <1.5) and over-anticoagulation (INR >5.0) occurred equally frequently in both the telecontrol and the conventional control groups. Our study, however, was not powered to detect differences under this approach.

Safety results indicated that patients in the telecontrol group showed significantly fewer adverse events than patients in the conventional control group. Similar results have been described in other trials [15,17,18], and other studies have demonstrated that the number of complications increases in parallel with the time that patients are outside therapeutic INR target range and with the occurrence of serious under- and over-anticoagulation [13,30,31]. Nevertheless, some other trials have shown that OAT self-control is as safe as conventional control [8,14,16,19,20].

Conclusion

In conclusion, results of this study indicate that OAT management with the Internet-based telecontrol tool SintromacWeb is an effective and safe management system for those patients who are able to use it, based on clinical criteria. SintromacWeb is a system that has been previously validated, and it is fully operative and currently in use in a hospital, which adds value to the applicability of the study results to OAT patients eligible for telecontrol management.

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Conflicts of Interest

This study was supported by Grifols. SintromacWeb is an Internet-based software developed by Grifols. The authors state that they have no other interests that might be perceived as posing a conflict or bias in relation to this paper.

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Abbreviations

CRF: case report form

INR: International Normalized Ratio

OAT: oral anticoagulation therapy

POC: point-of-care

TTR: time in therapeutic range

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Original Paper

Are Parents Getting it Right? A Survey of Parents' Internet Use for Children's Health Care Information

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Abstract

Background: The use of the Internet to search for medical and health-related information is increasing and associated with concerns around quality and safety.

Objective: We investigated the current use and perceptions on reliable websites for children's health information by parents.

Methods: Following institutional ethics approval, we conducted a survey of parents/guardians of children presenting for day surgery. A 20-item survey instrument developed and tested by the investigators was administered.

Results: Ninety-eight percent of respondents reported that they used the Internet to search for information about their child's health. Many respondents reported beginning their search at public search engines (80%); less than 20% reported starting their search at university/hospital-based websites. Common conditions such as colds/flu, skin conditions and fever were the most frequently searched, and unique conditions directly affecting the child were second. Despite low usage levels of university/hospital-based websites for health information, the majority of respondents (74%) regarded these as providing safe, accurate, and reliable information. In contrast, only 24% of respondents regarded public search engines as providing safe and reliable information. Fifty percent of respondents reported that they cross-checked information found on the internet with a family physician.

Conclusions: An unprecedented majority of parents and guardians are using the Internet for their child's health information. Of concern is that parents and guardians are currently not using reliable and safe sources of information. Health care providers should begin to focus on improving access to safe, accurate, and reliable information through various modalities including education, designing for multiplatform, and better search engine optimization.

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KEYWORDS

Internet; pediatrics; health information technology

Introduction

The use of the Internet to search for medical and health-related information is increasing in Canada and worldwide [1-4]. Of major concern regarding the use of the Internet for health-related

issues is the quality of information found there. The information can be poor, and users may not be able to assess the quality and reliability of websites they are using [5]. Previous studies have shown that parents are using the Internet to search for health information for their children [4-9]. Parents' perceptions of the

quality, reliability, and usefulness of websites vary [5-10]. We undertook a survey to identify the habits of parents and guardians using the Internet to search for children's health information and to determine their knowledge of safe and reliable sites. The aim of this study was to understand the current use and patterns of access to reliable and accurate Internet-based health information by parents and guardians of children seen at our institution.

Methods

Ethics and Setting

Institutional approval was obtained before starting the survey, participants were informed that consent was implied by participation in the study.

Following a pilot among parents in January and February 2013, the survey took place between May and July 2013 in the parent waiting room of the Hospital for Sick Children, a pediatric tertiary care facility in Toronto, Canada. Surveys were conducted after the children had gone into the operating room.

Survey Design

A review of the literature discussing websites used by parents informed the development of the survey instrument. A 20-item survey instrument was constructed using the online tool, Qualtrics Offline (Qualtrics, LLC), based on previously published methodology for the design of surveys [11]. After pretesting was performed by the authors and a pilot was tested on parents, the final survey tool was loaded onto a tablet computer for administering to parents and guardians.

The final survey tool ([Multimedia Appendix 1](#)) elicited information on current patterns of Internet use by parents

searching for information on their child's health, types of devices used to access information, perceived reliability of websites and cross-corroboration of information, and future uses of the Internet for child's health information.

Sample Size Survey Distribution and Collection

With 16,000 surgical procedures performed in our institution annually, assuming a 95% confidence interval and an 8% margin of error, 149 participants were required. Our target population and sampling frame consisted of parents and guardians of children presenting to the preoperative waiting room for same day surgery and procedures. Excluded were parents who did not speak/understand English, those who declined to participate in the survey, and those who were employees at the hospital.

Three researchers conducted the survey and entered responses onto a tablet computer in real time; responses were then transferred to an Excel spreadsheet (Microsoft Corporation) for analysis.

Data Analysis

Data analysis was performed using Prism version 5.0b for Mac OS X (GraphPad Software); descriptive statistics were used to summarize the data.

Results

Demographics

Of the 146 parents agreeing to participate in the study, 125 (85.6%) spoke English as their first language ([Table 1](#)). Most parents (108, 74.0%) reported that their child had been previously admitted to the hospital or attended an emergency/walk-in clinic.

Table 1. Primary language of respondents.

Primary Language	n (%)
English	125 (85.6)
Spanish	5 (3.4)
Farsi	3 (2.1)
Arabic	2 (1.4)
Gujarati	2 (1.4)
Albanian	1 (0.7)
Bulgarian	1 (0.7)
Chinese	1 (0.7)
Hindi	1 (0.7)
Hungarian	1 (0.7)
Persian	1 (0.7)
Somali	1 (0.7)
Twi	1 (0.7)

Current Use of the Internet

Almost all parents (143, 97.9%) reported using the Internet to search for health information regarding their child. Parents

reported being most familiar with public search engines as a source of health information (117, 80.1%) and least familiar with child-specific websites run by healthcare professionals (39, 26.7%) ([Figure 1](#)). Forty-three percent of respondents

reported that they searched for health information regarding their child frequently, between a few times a month to every day (Figure 2). Parents reported using laptop computers, desktop computers, mobile phones, and tablets in almost equal

proportions (90, 61.6%; 77, 52.7%; 67, 45.9%; and 63, 43.2%, respectively). Only 34.9% of respondents (51) reported that they knew our facility had a website dedicated to information on children’s health.

Figure 1. Respondents’ familiarity with various websites for access to information on children’s health.

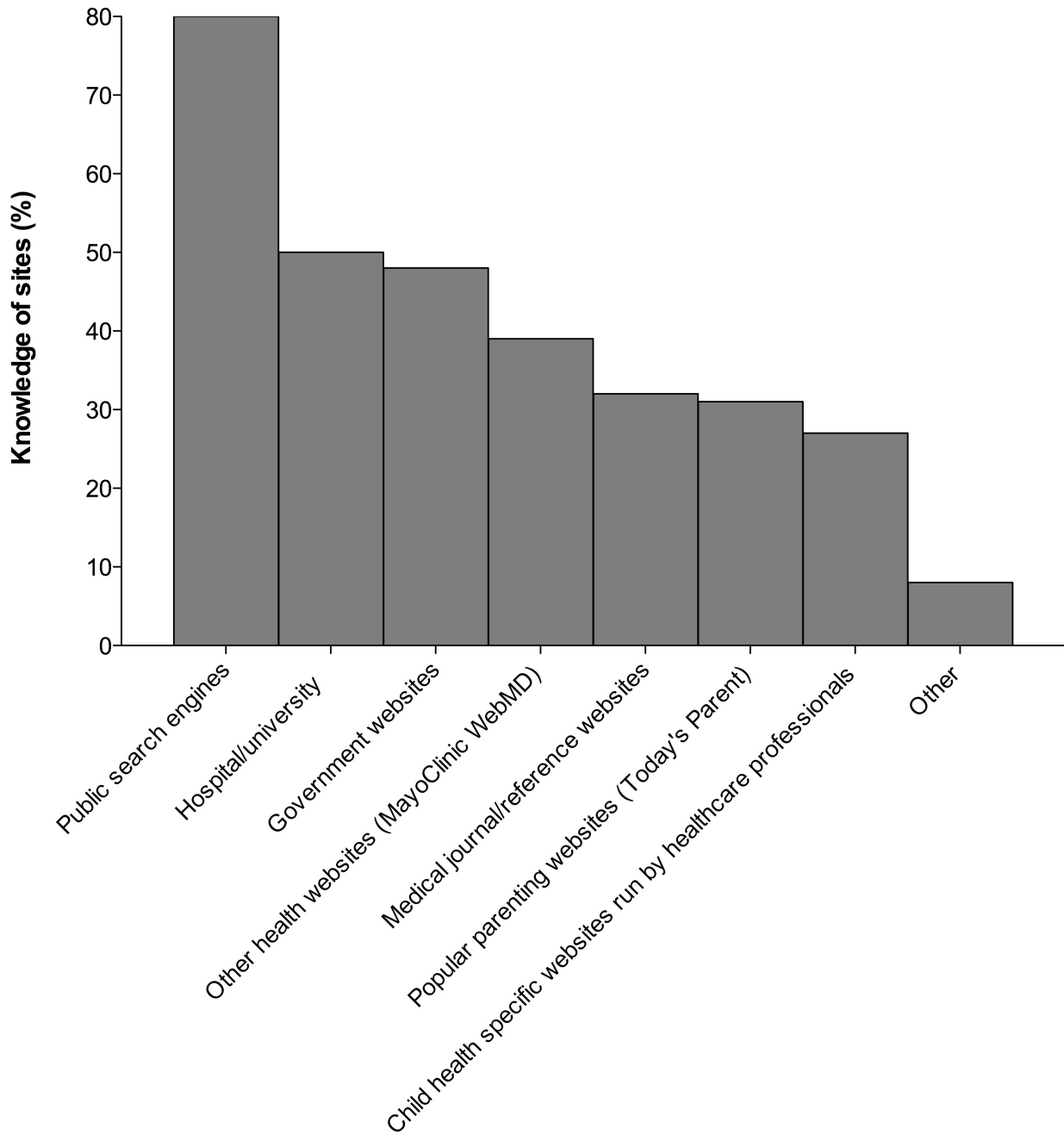
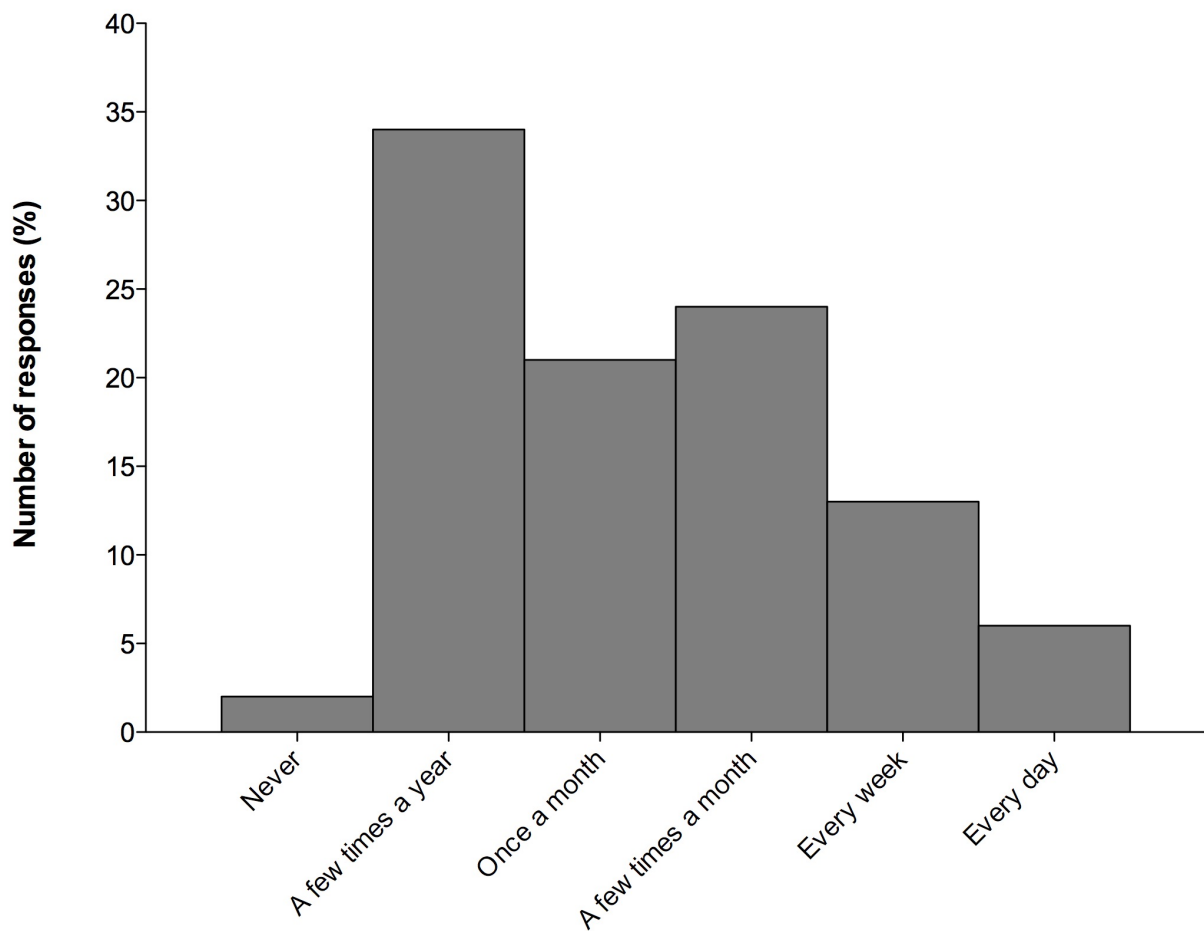


Figure 2. Frequency of Internet use for health related information.

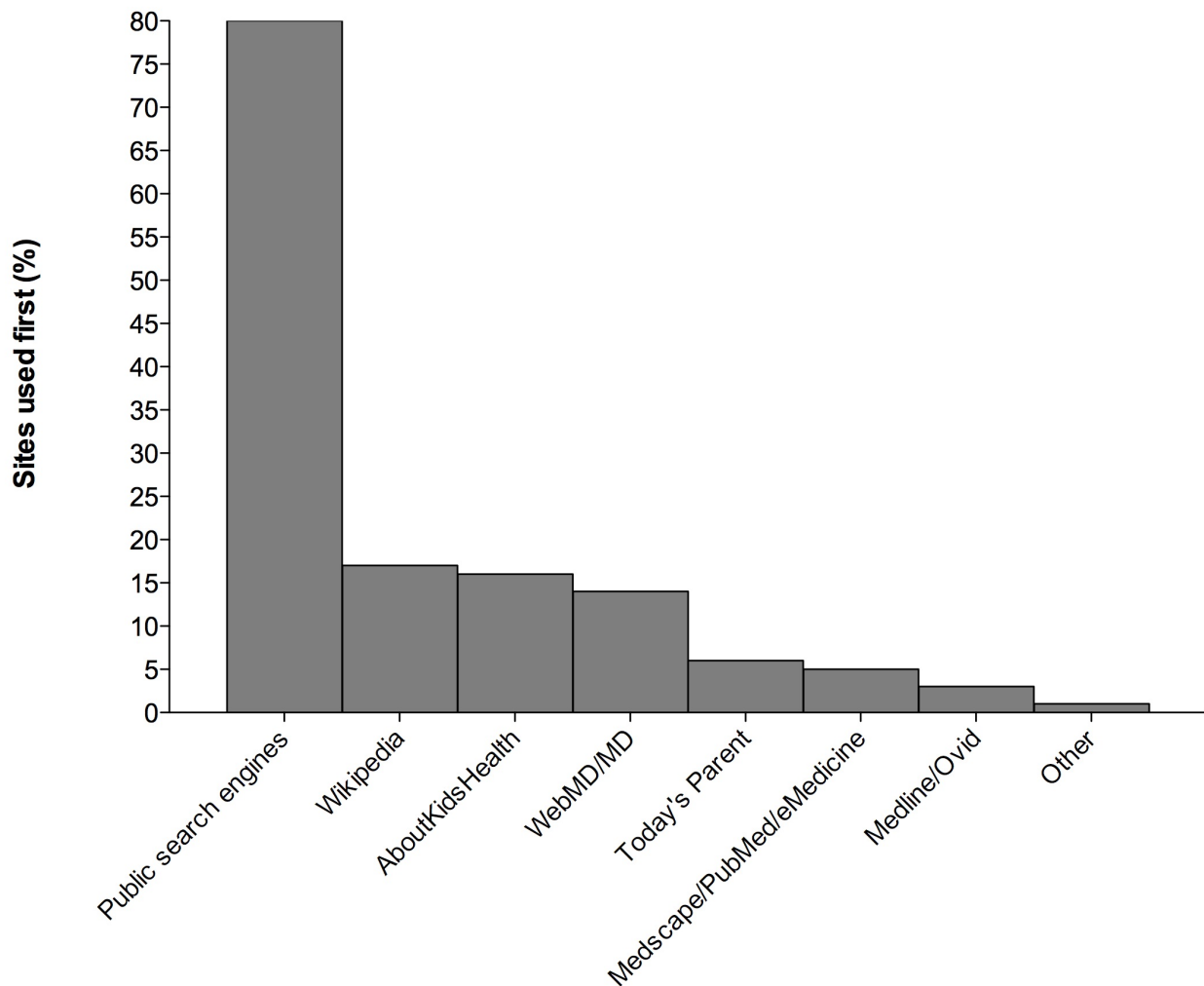
Characterizing Use of the Internet

Public search engines were used as a starting point by 117 respondents (80.1%) (Figure 3). The majority of parents (126, 86.3%) reported searching for information on common conditions such as colds/flu, skin conditions, and fever; only

23 (15.8%) reported seeking information about surgical/diagnostic procedures that were related to the child's presentation on the day of the study. A complete list of child health issues respondents reported searching about and reasons associated with the search is included in Table 2.

Table 2. Information sought and factors influencing Internet searching.

Search Topics	n (%)
General information	
Specific conditions	126 (86.3)
Surgical/diagnostic procedures	23 (15.8)
Child development	15 (10.3)
Diet/feeding	7 (4.8)
Medications/treatments	4 (2.7)
Child behavior	3 (2.1)
Specific conditions	
Cough, cold, flu	22 (15.1)
Skin conditions (rash, eczema, acne)	22 (15.1)
Fever	19 (13.0)
Cancer	16 (10.9)
Allergies	13 (8.9)
Congenital heart disease	9 (6.2)
Asthma	9 (6.2)
Eye conditions (strabismus, cataracts)	9 (6.2)
Abscesses, cysts	9 (6.2)
Gastrointestinal (vomiting, diarrhea)	9 (6.2)
Hypospadias	7 (4.8)
Chromosomal abnormalities	7 (4.8)
Diabetes	6 (4.1)
Cleft lip/palate	6 (4.1)
Bone lesions	6 (4.1)
Reasons for searching	
Health concern/question	99 (67.8)
Upcoming surgery/procedure	7 (4.8)
New diagnosis	4 (2.7)
New medication/treatment	4 (2.7)
Need for additional information not provided by health care practitioner	4 (2.7)
Urgent need for information	4 (2.7)
Availability of doctor	4 (2.7)

Figure 3. Sites first accessed for health-related information.

Perceptions on Reliability of Websites and Information

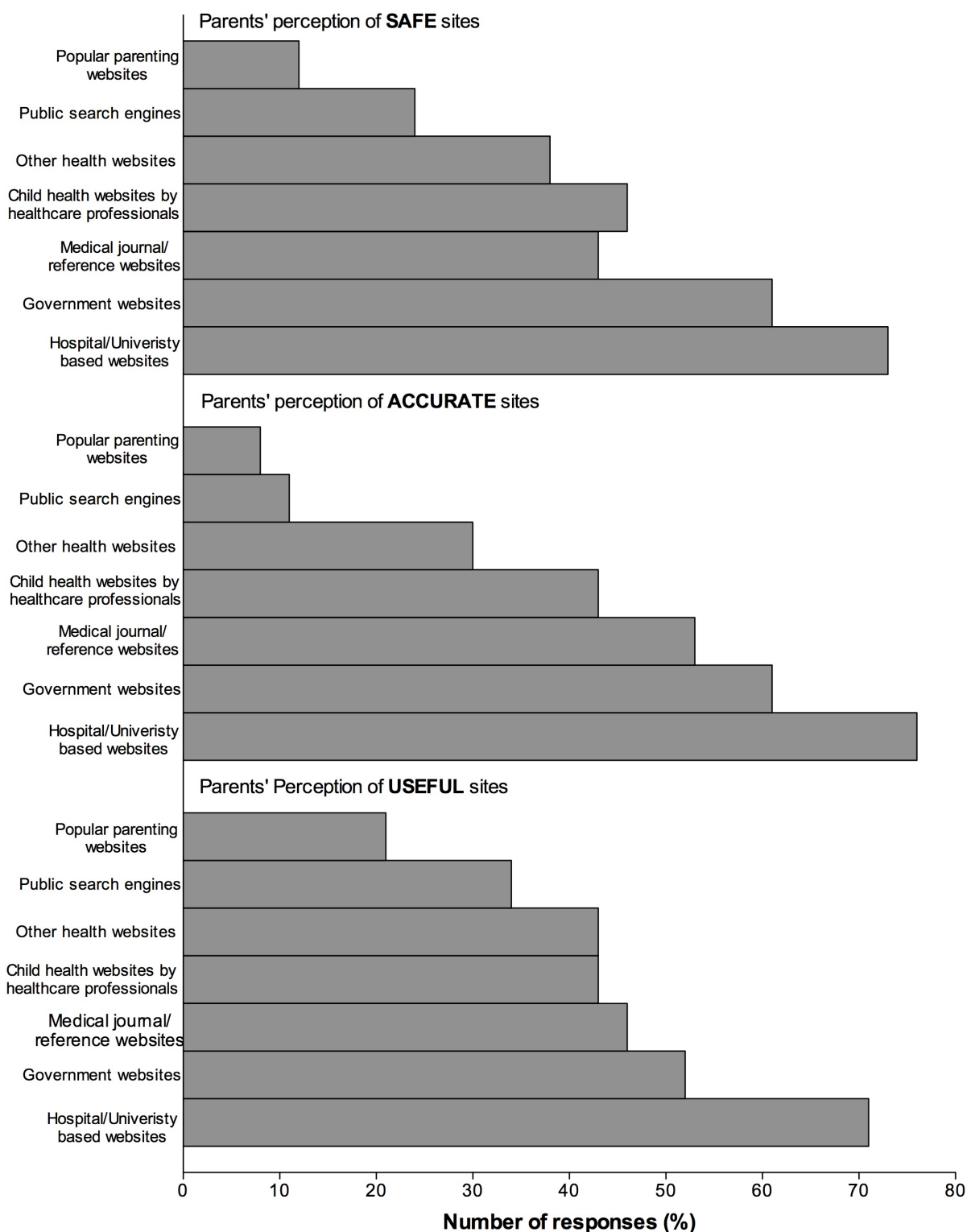
Parents reported that they regarded hospital/university websites as safe, accurate, and useful sources of health-related information (105, 71.9%; 104, 71.2%; and 111, 76.0%, respectively). Very few parents regarded public search engines and popular parenting websites as safe sources (35, 23.9% and 18, 12.3%, respectively) or accurate sources (16, 11.0% and 12, 8.2%, respectively) (Figure 4). Fifty-one percent of parents (74

reported that they crosschecked health-related information found on the Internet with a family physician, with a pediatrician (67, 45.9%), family (64, 43.8%), friend/family in healthcare (54, 37.0%) and friends (45, 30.8%). Regarding future use of the Internet (in the next 12 months) for child health information, 112 (76.7%) of parents reported that they were likely to use our facility's website following this study and 82 (56.1%) reported that they will continue to access and cross-check information found through public search engines (Table 3).

Table 3. Websites parents were likely to use in the future for their child health information and crosscheck information they found.

Primary sources, n (%)	Not likely	Neutral	Likely	No answer
Hospital/university-based websites	44 (30.1)	15 (10.3)	83 (56.8)	4 (2.7)
Medical journal/reference websites	64 (43.8)	22 (15.1)	56 (34.8)	4 (2.7)
Government websites	36 (24.7)	19 (13.0)	84 (57.5)	7 (4.8)
Public search engines	16 (11.0)	19 (13.0)	107 (73.3)	4 (27.3)
Other health websites	61 (41.8)	10 (6.8)	65 (44.5)	10 (6.8)
Popular parenting websites	82 (56.2)	14 (9.6)	39 (26.7)	11 (7.5)
Likely to cross-check information from the following websites, n (%)				
Hospital/university-based websites	33 (22.6)	14 (9.6)	93 (63.7)	6 (4.1)
Medical journal/reference websites	38 (26.0)	21 (14.4)	81 (55.5)	6 (4.1)
Government websites	36 (24.7)	19 (13.0)	85 (48.2)	6 (4.1)
Public search engines	16 (11.0)	19 (13.0)	107 (73.3)	6 (4.1)
Other health websites	40 (27.7)	15 (10.3)	81 (55.5)	10 (6.8)
Popular parenting websites	39 (26.7)	14 (9.6)	81 (55.8)	12 (8.2)

Figure 4. Parent’s perception of safe, accurate and useful websites.



Discussion

Principal Findings

The results of our study demonstrate that almost all respondents use the Internet to search for child health information. Of the 97.9% (143) of parents and guardians who use the Internet to search for information, almost half were frequent users who

searched anywhere from a few times a month to every day. This represents a significant increase in the use of the Internet compared to previous studies [4,6-9]. The use of the Internet by parents of patients in pediatric tertiary care centers in Australia, Canada, and the United States rose from 40% to 71% between 2003 and 2006 [4,6-9]. The continued rise reflected in our findings may be explained in part by the proliferation of high speed Internet in homes and on mobile devices. In addition,

parents are increasingly taking an active role in their children's health care and using the Internet to seek information around their child's health [6]. The high level of use reported in our study may demonstrate the need for health care institutions and governments to continue to invest in the provision of online health care information about children for parents and guardians.

While the respondents participating in our study were at a tertiary care facility, the majority sought information on common childhood ailments (cold/flu, skin conditions, and fever) with a surprisingly smaller proportion (23, 15.7%) searching for information about an upcoming surgery or procedure. The development of web content pertaining to common conditions may remain a key focus for health care providers, web content developers and public health officers.

The majority of respondents reported that they use public search engines to search for health-related information for their child. Despite the choice of public search engines to search for health-related information, respondents rated public search engines low in terms of providing access to safe and accurate information. The use of the public search engines to search for health-related information raises concerns as several authors have reported the quality of health information found on the Internet to be poor [5,12-15]. Public search engine results provide links to various information sources that may result in misinformation, information overload, mistrust in the health care system by the parents and guardians, and potential detrimental effects on a child's health. Respondents in our study identified government, university, and hospital-based websites as sources of safe, accurate, and reliable information; however, they also reported being less likely to access these websites for health-related information. A possible reason is that parents may not know of the existence of government, university, and hospital-based websites that would provide such valuable, safe, accurate, and reliable information. Previous studies have reported that parents and guardians would appreciate some guidance about searching for information on the Internet [4]. Health care providers can meet that need by providing lists of reliable websites through print, email newsletters, television, and radio drives [15]. Search engine optimization of websites can increase their visibility in search results, important because anecdotal evidence suggests that users do not navigate past the first page of results.

Our study demonstrates that almost half of respondents reported that they cross-checked information found online with a family

physician. Reasons for this may include a desire to check the reliability and accuracy of information or get clarification. This cross-check could potentially be linked to a telehealth presence, chat line, or mobile apps to help parents who have questions or concerns about what they have read about on the Internet.

Future Use of the Internet by Parents

Respondents in our study reported they were likely to continue to use desktop computers, laptops, tablet devices, and smart phones in almost equal proportions to search for information on their children's health. Health information providers should consider designing websites that can be viewed and navigated easily on multiple platforms.

Limitations

We used a convenience sample of parents of children presenting for surgery at a tertiary care hospital, so it is possible that the results may not reflect the general population. It would be important, when developing websites for individual facilities, that a needs assessment be done to ensure that the information contained on the website meets the needs of the intended audience.

We excluded parents who did not read and understand English. The patterns of Internet use may be influenced by culture and language, something our study did not investigate.

Finally, we relied on parents to self-report sources they access, which may be associated with recall bias. Our study had a large sample size and adequate response rate providing meaningful data for analyses and drawing significant findings and conclusions.

Conclusions

Our study demonstrates that almost all parents are using the Internet to seek health care information related to their children. Information sought is largely related to general childhood health issues and development. Parents do not routinely use websites that are known to provide safe, accurate, and reliable information. Health care providers should focus on improving access to safe, accurate, and reliable information for parents and guardians. The development by policy makers of resources to educate parents and guardians on how to use the Internet to search for health information may aid in improving this area of medicine.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Parent survey.

[PDF File (Adobe PDF File), 89KB - [ijmr_v4i2e12_app1.pdf](#)]

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Original Paper

Web-Based and Telephone Surveys to Assess Public Perception Toward the National Health Insurance in Taiwan: A Comparison of Cost and Results

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Abstract

Background: Numerous studies have examined the impact of global budget payment systems of health insurance on patient access to medical care. In order to monitor the population's accessibility to health services, a series of survey are often used to understand public perceptions of the health care provider. Taiwan implemented the single-payer National Health Insurance in 1995 and has been conducting a series of surveys to monitor public perception of the NHI after adopting a global budget payment system in 2002. Although telephone surveys are commonly used in obtaining public opinions on various public health issues, limitations such as higher cost and influence of interviewers do raise some concerns. Web-based surveys, one of the alternative methods, may be free from these problems.

Objective: Our aim was to examine the difference of sociodemographic characteristics, satisfaction of NHI and NHI-contracted health care providers, attitude toward NHI-related issues, behavior in seeking medical advice and self-reported health status between those who completed Web-based surveys and those reached by telephone.

Methods: This study compared the demographic factors of participants who took either a Web-based survey (1313 participants) or random digit dialing telephone survey (2411 participants) that contained identical questions.

Results: Compared to telephone survey respondents, Web-based respondents tended to be younger ($P<.001$), unmarried ($P<.001$), non-smokers ($P<.001$), with a higher education ($P<.001$), and a higher monthly household income ($P<.001$) and worse self-reported health status ($P=.008$); however, they were less likely to report suffering from a chronic disease ($P<.001$). Despite these differences in background characteristics, no significant differences were observed in their answers related to the seeking of medical care or NHI-related issues. Telephone survey respondents reported greater satisfaction with NHI services. Web-based surveys were also shown to provide a lower average cost per sample (US\$0.71) compared to telephone surveys (US\$3.98).

Conclusions: Web-based surveys provide a low-cost alternative method for the polling of public attitudes toward NHI-related issues. Despite general similarities between the two polling methods with regard to responses, respondents to telephone surveys reported a stronger agreement with regard to satisfaction with NHI services and a more positive self-reported health status.

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KEYWORDS

Web-based survey; telephone survey; public perception; National Health Insurance; self-reported health status

Introduction

Background

Health care systems often use the reform of payment system to create incentives for health care providers to provide only necessary service within a limited budget which could have influence on population's accessibility to health care. Numerous studies have examined the impact of global budget system on access to health care. Iglehart et al found that after introducing a global budget, changed allocation of local physicians affected accessibility to medical care [1]. Chu et al also indicated that active suppression of medical expenditures curtailed access to medical care due to bed closures [2]. Many countries use surveys as a monitoring measure aimed at ensuring equity in access to medical care. The Agency for Healthcare Research and Quality (AHRQ) in the United States developed the Consumer Assessment of Healthcare Provider and Systems (CHAPS) with the aim of measuring, reporting on, and improving the quality of health care from the perspective of consumers and patients [3]. Similarly, the Department of Health in the United Kingdom (UK) has been conducting surveys regarding public perceptions of the National Health Service (NHS) and the GP Patient Survey [4,5].

Taiwan implemented a National Health Insurance (NHI) system in 1995 and implemented a global budget payment system in 2002 to contain skyrocketing medical expenditures. The NHI system is a single-payer system which covers more than 99% of residents and contracts with more than 90% of the hospitals and clinics. Like other countries, Taiwan's National Health Insurance Administration (NHIA) has been conducting a series of surveys on public perception toward the NHI since 2002. The aim of this series of surveys is to understand public perception regarding NHI and health care services and to track how perceptions have changed over time. Questions in this series of surveys comprise core and optional items. Core items are included in every iteration of the annual survey, while optional items are designed specifically for current topics of interest. Every year, telephone survey data are collected using a computer-assisted telephone interviewing (CATI) system, in which samples are selected using a random digit dialing (RDD) system.

A number of problems have been identified in these telephone surveys [6]. Evidence has shown that the gender and race of the interviewer can influence the results [7,8]. The attitude and demeanor of the interviewers may also bias the responses [9,10]. Despite the high response rates, telephone surveys are becoming increasingly expensive, which may be due to the time required to complete surveys using these methods [11]. One alternative to telephone surveys is to use the World Wide Web. Web-based surveys are more likely to be free from interviewer bias due to the nature of being self-administered. They also create a data input file directly. Information obtained from Web-based surveys displays higher test-retest reliability than do telephone surveys [12]. Previous studies have suggested that respondents to Web-based surveys are more likely to describe their personal habits such as drinking [13,14], as well as their concerns regarding traffic safety [15]. This approach also raises concern

about the comparability of information obtained using Web-based surveys with that obtained by telephone surveys. Telephone surveys generally obtain a representative national sample; however, Web-based surveys are restricted to respondents who have Internet access.

Study Aims

To the best of our knowledge, no previous study has examined the differences between Web-based surveys and telephone surveys regarding perceptions of NHI or NHI-contracted health care providers and self-reported health status. Our aim was to examine the difference of sociodemographic characteristics, satisfaction of NHI and NHI-contracted health care providers, attitude toward NHI-related issues, behavior in seeking medical advice and self-reported health status between those who completed Web-based surveys and those reached by telephone.

Methods

Development of Questionnaires

To obtain the data necessary to answer the study questions, we formulated a cross-sectional data collection framework using the telephone and internet as communication media. Both survey methods were conducted in August-September 2013. All people aged 20 or older in any region of Taiwan were eligible to take the survey. Screening was conducted by asking respondents whether they were 20 years of age.

The conceptual framework of questionnaires incorporated seven dimensions: satisfaction, health status, use of health service, personal health practice, need for health care, enabling resources, and predisposing characteristics. The draft version of the questionnaire was first reviewed by five experts to enhance content validity. Based on their suggestions, we modified the wording and items on the questionnaires. Then, a pre-test with small sample size was executed to examine the internal reliability of questionnaires. The Cronbach alpha coefficients of these seven dimensions were between .5 and .8. The final questionnaires included 43 items aimed at measuring satisfaction with the NHI and NHI-contracted health care providers, attitudes toward NHI-related issues, use of health service, health status (SF-8 health survey), health behaviors (eg, smoking, drinking, and chewing betel nuts), sociodemographic characteristics, and medical history.

The contents of the Web- and telephone-based questionnaires were identical in terms of the questions asked, the wording, and the order of presentation. The study protocol was approved by the ethics committee at National Taiwan University Hospital (IRB number: 1000401).

Telephone Interview Survey

Individuals aged 20 years and older were eligible for interviews. Stratified random sampling procedure was used to draw respondents for telephone interviews. We contracted a company with experience in conducting telephone interviews; they used the RDD method with CATI to carry out the interview. All interviews were conducted from a central location, and the interviewing process was monitored by supervisors to control quality. All interviewers were well-trained individuals working

on a regular basis for the survey company. The household telephone number list was obtained from Chunghwa Telecom, a major provider in Taiwan. To improve the coverage rate and increase the chances of contacting of households that were not registered in the phone book, we randomly replaced the last two digits of the drawn telephone numbers with two different digits to form a new telephone number. If there were missing items, the telephone interviewers would connect participants again to complete the questionnaires. At the end of the survey, the total number of usable responses was 2411 with a sampling error of 2.0%.

Web-Based Survey

The sampling lists used in the Web-based and telephone surveys were obtained from different suppliers to avoid overlap. The panel list used in the Web-based survey included 320,000 individuals who were also matched to the defined target population. The respondents were randomly drawn from panel members aged 20 and older and invited via email. In addition, interested participants could click on a hyperlink to access information related to the study. The participants were required to finish all the items on the questionnaires, and then they could join the lottery. Finally, we obtained 1313 usable responses with sample error of 2.7% in the Web-based survey.

Statistical Analysis

Data were analyzed using SAS version 9.3 for Windows (SAS Institute). Descriptive statistics were used to describe the difference between respondents in the telephone-based and Web-based groups. An independent sample *t* test and Pearson chi-square test were used to test whether the differences were statistically significant. A *P* value of less than .05 was considered statistically significant. Multivariate logistic regression and mixed linear regression models were used to test the differences in each dimension of the questionnaire by reporting their odds ratios, coefficients, and standard deviations.

Results

The demographic and clinical characteristics of all 3724 respondents are presented in Table 1. The respondents who filled out the Web-based questionnaire were generally younger ($P=.0001$), unmarried ($P<.001$), nonsmokers ($P<.001$) with a higher education level ($P<.001$) and higher monthly household income ($P<.001$), were less likely to suffer from chronic disease ($P<.001$), and were more likely to be living in the Taipei area ($P<.001$) when compared to respondents of the telephone survey.

Table 1. Characteristics of respondents who participated in the Web-based and telephone surveys (n=3724).

	Telephone (n=2411) frequency (%)	Web-based (n=1313) frequency (%)
Gender		
Male ^a	987 (40.9)	593 (42.5)
Female	1424 (59.1)	720 (54.8)
Age, years		
20-29 ^b	231 (9.6)	410 (31.2)
30-39	422 (17.5)	503 (38.3)
40-49	675 (28.0)	283 (21.6)
50-59	591 (24.5)	100 (7.6)
≥60	488 (20.2)	17 (1.3)
Unknown	4 (0.2)	0
Education		
Junior high school and below ^b	660 (27.4)	12 (0.9)
Senior high school	787 (32.6)	160 (12.2)
University	837 (34.7)	840 (64.0)
Graduated school	124 (5.1)	299 (22.8)
Unknown	3 (0.1)	2 (0.2)
Monthly household income		
No income ^b	51 (2.1)	17 (1.3)
NT\$1-29,999	336 (13.9)	126 (9.6)
NT\$30,000-\$59,999	749 (31.1)	432 (32.9)
NT\$60,000-\$90,000	434 (18.0)	297 (22.6)
NT\$90,000 and above	549 (22.8)	280 (21.3)
Unknown	292 (12.1)	161 (12.3)
Marital status		
Unmarried ^b	429 (17.8)	631 (48.1)
Married or cohabiting	1688 (70.0)	598 (45.5)
Other	287 (11.9)	73 (5.6)
Unknown	7 (0.3)	11 (0.8)
Religion		
No religion	685 (28.4)	418 (31.8)
Buddhism	1533 (63.6)	762 (58.0)
Christ Catholic	146 (6.1)	79 (6.0)
Other	33 (1.4)	19 (1.5)
Unknown	14 (0.6)	35 (2.7)
Comorbidity		
Hypertension ^b	314 (13.0)	64 (4.9)
Diabetes ^b	112 (4.7)	26 (2.0)
Lipoid metabolism	60 (2.5)	31 (2.4)
Heart disease ^b	64 (2.7)	11 (0.8)

	Telephone (n=2411) frequency (%)	Web-based (n=1313) frequency (%)
Profession		
Government or military employee ^b	155 (6.4)	208 (15.8)
Company or organization employee	890 (36.9)	546 (41.6)
Person in charge	159 (6.6)	32 (2.4)
Licensed professional	5 (0.2)	57 (4.3)
Professional union staff	139 (5.8)	18 (1.4)
Farmer or fisherman	92 (3.8)	2 (0.2)
Student	59 (2.5)	110 (8.4)
Homemaker	471 (19.5)	85 (6.5)
Unemployed	142 (5.9)	56 (4.3)
Retired	285 (11.8)	31 (2.4)
Other	0	150 (11.4)
Unknown	14 (0.6)	18 (1.4)
Drinking		
Never	845 (35.0)	447 (34.0)
Yes	1566 (65.0)	848 (64.6)
Unknown	0	18 (1.4)
Smoking		
Never ^b	1652 (68.5)	1018 (77.5)
Smoked, but not more than five packages	159 (6.6)	109 (8.3)
Smoked more than five packages	600 (24.9)	175 (13.3)
Unknown	0	11 (0.8)
Betel nut		
Never ^b	1981 (82.2)	1150 (87.6)
Tried only 1-2 times	123 (5.1)	112 (8.5)
Eaten previously, but not in the last 6 months	202 (8.4)	41 (3.1)
Eaten many times within the last 6 months	105 (4.4)	10 (0.8)
Exercise in past 2 weeks		
No	775 (32.1)	429 (32.7)
Yes	1636 (67.9)	844 (64.3)
Unknown	-	40 (3.0)
Residential area		
Taipei region ^b	793 (32.9)	524 (39.9)
Northern region	352 (14.6)	201 (15.3)
Central region	456 (18.9)	231 (17.6)
Southern region	357 (14.8)	137 (10.4)
Eastern region	60 (2.5)	29 (2.2)
KaoPing region	393 (16.3)	191 (14.5)

^a $P < .05$.^b $P < .001$.

Table 2 presents the satisfaction felt by participants toward NHI and NHI-contracted health care providers, as well as behavior patterns in use of health service. Telephone survey respondents were more likely than Web-based respondents to report a feeling of satisfaction with the NHI (58.4% vs 44.7%; adjusted odds

ratio [AOR] 1.97, 95% CI 1.62-2.40) and NHI-contracted health care providers (63.4% vs 48.4%; AOR 2.39, 95% CI 1.96-2.92). No significant differences were observed between telephone and Web-based survey respondents with regard to their behavior in use of health service.

Table 2. Comparison of Web-based and telephone survey respondents with regard to satisfaction with NHI and patterns in use of health service.

	Telephone %	Web-based %	AOR (95% CI) ^b
Satisfaction			
Satisfied with NHI ^a	58.4	44.7	1.97 (1.62-2.40)
Satisfied with NHI-contracted health care provider ^a	63.4	48.4	2.39 (1.96-2.92)
Use of health service			
Feel uncomfortable but did not seek medical care in the past 6 months (yes)	26.0	14.8	0.82 (0.67-1.00)
The most common place to seek medical care is your city of residence (yes)	94.4	92.8	0.77 (0.53-1.14)
Most recent case of seeking medical care using NHI card was as an outpatient visit (yes)	95.4	95.4	0.99 (0.61-1.62)
When you need to seek medical care, you go to a clinic (yes)	14.7	14.9	0.82 (0.67-1.00)

^aMeasured on a 5-point scale from 1 (very dissatisfied/disagree) to 5 (very satisfied/agree).

^bAOR indicates the relative likelihood that Web-based survey respondents indicated a concern for a given issue, obtained using multivariate logistic regression analysis after controlling for background characteristics (Table 1) and self-reported health status.

Table 3 illustrates the attitudes of respondents toward NHI-related issues. Results of logistic regression analysis indicate that, after accounting for sociodemographic factors, comorbidity history and self-reported health status, Web-based

respondents were more likely than telephone survey respondents to be aware of the details of the NHI policy on the programs specifically designed to assist the disadvantaged (41.1% vs 25.3%; AOR 1.86, 95% CI 1.52-2.27).

Table 3. Comparison of respondents to Web-based and telephone surveys regarding the degree to which they were concerned with NHI-related issues.

	Telephone %	Web-based %	AOR (95% CI) ^b
Counseling patients with highest number of ambulatory visits to see doctors in a specified institution ^a	86.3	91.1	1.21 (0.86-1.70)
I am aware of the details of NHI policy aimed at assisting the disadvantaged	25.3	41.1	1.86 (1.52-2.27)
I was inconvenienced when use of health service in the past 6 months	15.6	17.5	0.75 (0.53-1.06)
Increasing the copayment for emergency visits ^a	56.8	54.6	0.92 (0.76-1.12)
Referral to another hospital under the consent of patient ^a	77.9	76.7	0.73 (0.58-0.93)

^aMeasured on a 5-point scale from 1 (very dissatisfied/disagree) to 5 (very satisfied/agree).

^bAOR refers to the relative likelihood that Web-based survey respondents indicated a concern regarding particular issues, obtained using multivariate logistic regression analysis after controlling for the characteristics of respondents listed in Table 1 and self-reported health status.

Table 4 presents the self-reported health statuses of respondents of the two surveys. Web-based respondents generally had poorer health status with regard to physical functioning (adjusted difference: -1.73; $P < .001$), role-physical (adjusted difference: -2.25; $P < .001$), body pain (adjusted difference: -1.94; $P < .001$), social functioning (adjusted difference: -3.89; $P < .001$),

role-emotional (adjusted difference: -4.06; $P < .001$) and mental health (adjusted difference: -2.94; $P < .001$). However, Web-based respondents reported a higher degree of vitality (adjusted difference: 0.94; $P = .015$) than did the telephone survey respondents.

Table 4. Self-reported health status of respondents to Web-based and telephone surveys.

	Telephone, mean (SD)	Web-based, mean (SD)	Unadjusted difference, coefficient (P)	Adjusted difference ^a , coefficient (P)
Physical health				
Physical functioning	51.38 (6.42)	50.29 (5.12)	-1.09 ^d	-1.73 ^d
Role-physical	51.22 (6.25)	49.58 (4.86)	-1.64 ^d	-2.25 ^d
Body pain	56.38 (5.88)	54.95 (4.21)	-1.43 ^d	-1.94 ^d
General health	45.91 (8.09)	46.62 (7.41)	0.71 ^d	-0.18
Mental Health				
Vitality	45.67 (8.52)	47.01 (8.21)	1.34 ^c	0.94 ^b
Social functioning	52.48 (6.27)	48.16 (6.43)	-4.32 ^d	-3.89 ^d
Role-emotional	49.22 (6.35)	44.84 (6.12)	-4.38 ^d	-4.06 ^d
Mental health	52.44 (7.44)	49.00 (6.87)	-3.44 ^d	-2.94 ^d

^aAdjusted differences refer to the adjusted mean of Web-based surveys minus the adjusted mean of telephone surveys, which was obtained using mixed regression analysis after controlling for background characteristics of respondents (Table 1).

^b $P < .05$.

^c $P < .01$.

^d $P < .001$.

Discussion

Principal Findings

This study sought to determine whether a Web-based survey could be used as an alternative to RDD telephone surveys. Our results indicate substantial demographic and socioeconomic differences between the individuals who participated in the two surveys. Our findings are consistent with previous studies, in which Web-based survey respondents are generally younger, healthier, and more highly educated than respondents to telephone surveys [16,17]. This was not unexpected, due to the fact that elderly persons still lag behind other age groups with regard to internet usage [18]. The bias did not disappear after weighting according to sociodemographic factors. This raises concerns about the accuracy of Web-based surveys and how representative the information gained is of a population.

Comparison to Prior Work

This is the first study to compare Web-based and RDD telephone surveys with regard to different dimensions. Previous studies have demonstrated that the answers provided by respondents to Web-based surveys often differ from those provided by respondents to telephone surveys [15,19]; however, other studies showed no significant differences. Zuidgeest et al investigated differences between postal surveys and mixed-model surveys (Internet questionnaires with paper follow-up). Their findings failed to indicate any differences in global ratings of health care between respondents to the two surveys [20]. Braunsberger et al compared telephone and Web-based surveys with regard to test-retest reliability in which participants filled out two-wave questionnaires. Their results indicate that the reliability of data from Web panels exceeds that obtained from telephone survey panels [21]. Our results show that despite fundamental

differences between those who took the two surveys, behaviors with regard to use of health service and attitudes toward NHI-related issues were similar, except for the awareness of assisting the disadvantaged policy in NHI. This implies that the two data collection modes are able to obtain unbiased data related to these issues. However, if one would like to assess the public perceptions of health care system and population health status, the results from different survey modes could not be compared directly.

Previous studies showed that many of the satisfaction polls done in other countries focused more on assessing consumer and patient satisfaction with the use of health services but rarely assessed the public perception on the health care system. In terms of survey modes, most of the satisfaction surveys collected data via telephone, mail, face-to-face, or mixed methods. Recently, Web-based surveys with advantages of lower cost and more time saving have been broadly used in many fields. In the UK, for example, the GP patient survey used three different methods to collect data: paper, telephone, and Web. Their results indicated that the proportion of patients using Web-based survey was increasing.

Compared to previously mentioned polls done in other countries, this study demonstrated the feasibility of combining satisfaction toward use of health service with awareness and attitudes toward selected policies. Furthermore, we used both telephone and Web-based surveys to collect responses to the same questionnaire and examined whether the responses were comparable. The results indicate that, after adjusting for respondents' socioeconomic characteristics, use of health service, personal health practice, and health status, the satisfaction toward various issues was significantly different between respondents from telephone surveys and Web-based surveys. Moreover, results of this study also showed that

respondents to the telephone survey were more satisfied with NHI and NHI-contracted health care providers than those who took the Web-based survey. Previous studies have indicated that Web-based respondents tend to give more neutral or negative attitudinal evaluations [22]. Evidence also indicates that the techniques, gender, and race of the interviewer can bias the results [7,8]. Thus, it may be reasonable to expect that individuals engaged in a direct conversation with a telephone interviewer may show more positive attitude toward the issues discussed in the survey. Our findings also indicate that Web-based survey respondents are more aware of NHI policies. This is not unexpected considering the higher level of education held by these individuals and their greater access to information via the Internet.

In terms of self-reported health status, Rivara et al investigated the model effect of health-related quality of life among parents and children aged birth to 17 years using Web-based versus telephone surveys [23]. They found that the differences caused by model effect were small but statistically significant in some of the measures. Our findings are consistent with these studies, indicating that the self-reported health status of respondents to telephone surveys was significant better than those responding to Web-based surveys, after controlling for demographic and socioeconomic characteristics, health behaviors, and comorbidity history. When matched by demographic and socioeconomic characteristics and health behaviors, the differences between the two groups remained significant.

Previous studies have indicated that the cost of and time required to complete Web-based surveys (measured per respondent) are far lower than that of other methods [20,21,24]. In this study, the data obtained from the two survey methods was collected by the same commercial research firm. The overall cost of the telephone survey included the cost of acquiring and compiling

the survey data followed by preparation of a database for analysis as well as overhead and profit. The overall cost of the Web-based survey included the cost of contacting panel members, directing them to the survey site, creating a platform on which to conduct the survey as well as an allocation for overhead and profit. The average cost for each usable telephone survey sample was US\$3.98, whereas the average cost of obtaining each usable Web-based survey sample was US\$0.71, 17.8% of the cost of the telephone survey samples.

Nonetheless, several issues should be considered when interpreting these results. Any survey of perception and behavior is subject to various forms of self-selection and self-reported bias. As discussed earlier, the RDD telephone and Web-based surveys used in this study were not immune to these limitations. We attempted to minimize the effects of these issues by ensuring informed consent and standardized data collection procedures. Despite the fact that we employed an RDD contact method for the telephone survey, the contacted individuals were still able to choose whether to participate in the interview. Similarly, the Web-based survey, which required respondents to fill out the survey online, is prone to the issue of self-selection. Further research should address this issue by using a random assignment process to determine if the same population who agrees to be interviewed would choose a different format for the interview process.

Conclusions

Web-based surveys offer cost savings and efficiency in obtaining data, especially on awareness and attitudes toward NHI-related issues. But when assessing the public's satisfaction with the health care system and population health status, survey results could not be compared directly because different methods of survey could yield different outcomes.

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Conflicts of Interest

None declared.

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Abbreviations

- AOR:** adjusted odds ratio
- AHRQ:** Agency for Healthcare Research and Quality
- CATI:** computer-assisted telephone interviewing
- CHAPS:** Consumer Assessment of Healthcare Provider and Systems
- NHI:** National Health Insurance
- NHIA:** National Health Insurance Administration
- NHS:** National Health System
- RDD:** random digit dialing
- UK:** United Kingdom

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Original Paper

A Virtual Microscope for Academic Medical Education: The Pate Project

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Abstract

Background: Whole-slide imaging (WSI) has become more prominent and continues to gain in importance in student teaching. Applications with different scope have been developed. Many of these applications have either technical or design shortcomings.

Objective: To design a survey to determine student expectations of WSI applications for teaching histological and pathological diagnosis. To develop a new WSI application based on the findings of the survey.

Methods: A total of 216 students were questioned about their experiences and expectations of WSI applications, as well as favorable and undesired features. The survey included 14 multiple choice and two essay questions. Based on the survey, we developed a new WSI application called Pate utilizing open source technologies.

Results: The survey sample included 216 students—62.0% (134) women and 36.1% (78) men. Out of 216 students, 4 (1.9%) did not disclose their gender. The best-known preexisting WSI applications included Mainzer Histo Maps (199/216, 92.1%), Histoweb Tübingen (16/216, 7.4%), and Histonet Ulm (8/216, 3.7%). Desired features for the students were latitude in the slides (190/216, 88.0%), histological (191/216, 88.4%) and pathological (186/216, 86.1%) annotations, points of interest (181/216, 83.8%), background information (146/216, 67.6%), and auxiliary informational texts (113/216, 52.3%). By contrast, a discussion forum was far less important (9/216, 4.2%) for the students.

Conclusions: The survey revealed that the students appreciate a rich feature set, including WSI functionality, points of interest, auxiliary informational texts, and annotations. The development of Pate was significantly influenced by the findings of the survey. Although Pate currently has some issues with the Zoomify file format, it could be shown that Web technologies are capable of providing a high-performance WSI experience, as well as a rich feature set.

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KEYWORDS

whole-slide imaging; WSI; virtual microscopy; telepathology; e-learning; databases; Internet; microscopy

Introduction

Background

Whole-slide imaging (WSI), also known as virtual microscopy, has become more and more important in e-learning during the past decade. It is being used for general educational purposes, graduate education, pathology training, tutoring, and virtual workshops [1]. In many settings, WSI has already replaced the conventional microscope [1]. Recognizing the potential benefits of such applications for medical education, we conducted a survey to determine students' expectations of WSI applications for teaching purposes. Based on these findings, a WSI application for pathological specimens—the Pate application [2]—has been developed. The primary goal of developing Pate was to provide a tool that enables students to improve their skills in identifying histomorphological and pathological features on virtualized histological slides. Furthermore, Pate offers the possibility to explain the pathogenesis and pathophysiology of diseases on the basis of the morphological correlation.

Preexisting Applications

There already exist several WSI applications for histological and histopathological training, mainly the following: (1) Histologiekurs [3] from Zurich University, Switzerland, (2) Mainzer Histo Maps [4] from the Johannes Gutenberg University Mainz, Germany, (3) NYU Virtual Microscope (NYUVM) [5] from New York University, USA, (4) ScanScope Images [6] from Zurich University, Switzerland, (5) Virtuelle Pathologie Magdeburg [7] from the Otto von Guericke University, Magdeburg, Germany, (6) vMic [8] from Basel University, Switzerland, and (7) VSlides (Pathorama) [9] from Basel University, Switzerland.

As a basic characteristic of WSI, all these applications support latitude in the slide with a varying degree of usability. Some of the applications, such as ScanScope Images, Histologiekurs, and Mainzer Histo Maps, support annotations. Furthermore, Histologiekurs provides background information about the donor, informational texts about the specimen as well as support for points of interest. However, none of the listed applications, except NYUVM, support small-screen devices or a touch interface. Several of these WSI applications use Adobe Flash to implement the client. This requires the user to install a browser plug-in before using the application. Moreover, many recent devices, such as any Apple mobile gear, do not support those plug-ins. WSI applications using proprietary plug-ins include vMic, Mainzer Histo Maps, ScanScope Images, and VSlides. In contrast, there are also WSI applications that use Hypertext Markup Language 5 (HTML5) technologies. These include the applications NYU Virtual Microscope and Virtuelle Pathologie Magdeburg. By using HTML5 technologies, these applications avoid the disadvantages of browser plug-ins.

Most applications—Flash, Silverlight, and HTML5 based alike—miss important features, such as points of interest (POI), advanced annotations, informational texts, or a map scale. They provide basic image presentation capabilities, but fail to support important features provided by the WSI technology.

Demand Assessment

Due to the variety of options offered by new WSI technologies [10-12], it was a major prerequisite for a new WSI tool to investigate which features would benefit students, without compromising the usability of Pate. Therefore, the users' opinions were crucial in identifying and eliminating undesirable features. To achieve this goal, a survey was conducted targeted to functional needs and usability from students' perspectives as potential users of a new WSI tool. Therefore, their expectations of Pate, their experiences with already existing WSI tools, positive and negative features, as well as feature suggestions were analyzed by a questionnaire.

Slide Acquisition

As stated by Glatz-Krieger et al [8], the quality of virtual slides is defined by four crucial parameters, namely, the quality of the histological section, the completeness of the histological section, the quality of the scanned image, and the usability of the virtual slides. From these parameters, the quality and completeness of the section should be guaranteed during the physical slide acquisition. These parameters are essential for high-quality slide imaging.

Image Quality

The image quality is highly influenced by optical focusing during slide scanning. For this, two main methods are currently available. The first method utilizes stacking of multiple planes with different focus settings—z-stacking [13]—which emulates a physical microscope more closely [14]. This method also leads to more memory consumption. However, the slide acquisition process is less complicated, since only the middle optical plane needs to be positioned near the mean focal plane of the glass slide.

The second method uses a single virtual focal plane that resembles the best focus throughout the whole glass slide. Because this procedure results in smaller memory consumption, it was chosen for digitizing the histopathological slides for Pate. In order to ensure optimal results, we manually inspected the suggested automatically generated focal points of the software and corrected them where necessary.

Usability

Features for optimal usability are smoothly scrolling images, short access times, orientation, and several options for magnification. Furthermore, a good user interface design is of major importance. To achieve this, we put special emphasis on mobile devices next to the classical desktop. Therefore, we wanted to support small screens as well as a touch interface.

Resources

The Pate suite offers a family of differently scaled versions for each of the high-resolution images [15]. Thus, a user can conveniently choose the scale of interest while having fast response times due to the small bandwidth used during data transfer. This multiresolution representation can be obtained by a cascade of downsampling operations on a dyadic grid similar to the discrete Haar-wavelet decomposition of rasterized images [16]. At first sight, providing a family of images for different resolutions appears inefficient in terms of memory usage. As

we will show, the storage size of the multiresolution representation of images used with tiles is bounded by merely 133% of the original image size.

Every downsampling operation halves the length of the given images for each of the two dimensions. Thus, the overall number of pixels is quartered every iteration. Consider the sequence, $(s_i)_i$, of relative sizes according to the original image size, S :

$$(s_i)_i = (1, 1/4, 1/16, 1/64, \dots) = (q^0, q^1, q^2, q^3, \dots), \text{ where } q=1/4.$$

As a result, the overall size, M , can be written in terms of a finite geometric series, as displayed in [Figure 1](#).

Figure 1. The overall size M can be written in terms of a finite geometric series, where N is the number of downsampling operations.

$$M = S \sum_{k=0}^{N-1} q^k < S \sum_{k=0}^{\infty} q^k = \frac{S}{1-q}$$

The expression for M is overestimated by the (infinite) geometric series for $N \rightarrow \infty$ which converges for all q satisfying $0 \leq q < 1$ [17]. For the choice, $q=1/4$, the overall memory consumption relative to the original image size is obtained as $M/S < 4/3$. Thus, all resolutions can be stored with less than one-third of additional memory.

Methods

Student Survey for the Expectations of a Virtual Microscope

The student survey was designed in cooperation with the Center for Quality Assurance and Development of the Johannes

Gutenberg-University Mainz, Germany. It featured 16 items with question types including multiple choice, free field, and single choice. A total of 216 students in the third year—fifth and sixth semesters—of medical education participated in the survey. Of these, 62.0% (134/216) were female, 36.1% (78/216) were male, and 1.9% (4/216) did not disclose their gender. At the time of the survey, all students were participating in either the course General Pathology or Special Pathology. Prior to this, in their second year of medical education, all students had already completed a histological course. The voluntary survey was conducted during the first lecture of the course and included all the students of the year.

The survey aimed to investigate students' expectations of a virtual microscope with a view to the functional needs, such as useful features (eg, points of interest, annotations) and usability questions (eg, user-friendly handling). Furthermore, their experiences with already existing WSI applications were registered. Besides establishing baseline data, including gender, age, and time-based Internet usage, items were included that covered preexisting WSI experiences by asking for prior WSI usage. In addition, students were required to specify which applications were already known. Furthermore, we asked for expectations by enumerating items, which could be chosen if considered important. Finally, a free-field item for the students' own suggestions completed the survey. The entire set of items is given in [Table 1](#)—see [Multimedia Appendix 1](#) for a detailed description of the variables.

Table 1. Descriptive analysis of the dataset of the questionnaire.

Variable ^a	Number of observations, n	Mean	SD	Kurtosis	SE
Gender	212	0.6321	0.4834	-1.7122	0.0332
Age	213	1.1455	0.3535	1.9941	0.0242
InternetAccess	207	1.2995	0.7420	4.4098	0.0516
InternetUsage	207	2.5556	0.7731	-0.4041	0.0537
InternetCompetency	205	2.3415	1.0197	1.6230	0.0712
WSIUsage	201	2.3881	1.0529	1.5121	0.0743
AdvantagesForTests	204	1.0490	0.2937	36.2616	0.0206
Workplace	200	1.4100	0.7842	0.1971	0.0555
D_PC	216	0.3194	0.4673	-1.4150	0.0318
D_Laptop	216	0.8426	0.3650	1.4978	0.0248
D_Phone	216	0.0000	0.0000	N/A ^b	0.0000
D_Tablet	216	0.0231	0.1507	37.8429	0.0103
OfflineVersion	198	1.2020	0.4025	0.1709	0.0286
UsabilityWSI	203	2.5813	1.0230	0.1626	0.0718
ImageQualityWSI	205	2.3756	1.1204	0.5234	0.0783
F_BackgroundInfo	216	0.6759	0.4691	-1.4493	0.0319
F_Forum	216	0.0417	0.2003	18.8398	0.0136
F_Lattitude	216	0.8796	0.3261	3.3850	0.0222
F_HAnnotations	216	0.8843	0.3207	3.7083	0.0218
F_PAnnotations	216	0.8611	0.3466	2.3118	0.0236
F_POI	216	0.8380	0.3693	1.3245	0.0251
F_TeachingTexts	216	0.5231	0.5006	-2.0007	0.0341
K_MHM	216	0.9213	0.2699	7.6916	0.0184
K_Histoweb	216	0.0741	0.2625	8.4730	0.0179
K_HistonetUlm	216	0.0370	0.1893	21.8072	0.0129
K_Histology	216	0.0000	0.0000	N/A	0.0000
K_HistonetMarburg	216	0.0139	0.1173	66.3673	0.0080
K_HistoWebAtlas	216	0.0185	0.1351	48.5383	0.0092
K_vMic	216	0.0139	0.1173	66.3673	0.0080
K_Pathorama	216	0.0046	0.0680	209.0277	0.0046
K_virtPatho	216	0.0046	0.0680	209.0277	0.0046
K_NeoCortex	216	0.0000	0.0000	N/A	0.0000
K_AVKurs	216	0.0000	0.0000	N/A	0.0000
K_Histologiekurs	216	0.0046	0.0680	209.0277	0.0046
K_other	216	0.0694	0.2548	9.3594	0.0173

^aSee [Multimedia Appendix 1](#) for a detailed description of the variables.

^bNot applicable (N/A).

Development of the Client

The client application was implemented using JavaScript, HTML5, and Cascading Style Sheets (CSS). As JavaScript implementations differ by browser engine [18], the frameworks JQuery 1.7.1 (jQuery Foundation), MochiKit 1.4.2 (Mochi

Media), and Modernizr 2.5.3 were used to abstract JavaScript code from the browser implementation. OpenLayers 2.12 was employed to display image slide data.

Development of the Backend

To speed up application development, the backend was developed using the Web Server Gateway Interface abstraction layer. Python 2.7 (Python Software Foundation) was used as the programming language in combination with the TurboGears 2.2 framework. The database is hosted by a MySQL Server 5.1.66 (Oracle Corporation, Redwood Shores, CA).

Slide Acquisition

We decided to use a single, virtual plane of focus throughout the physical glass slide. This method proved to be more difficult in maintaining a good focus throughout the slide than initially assumed. The autofocus functionality only provided a rough starting point resulting in the need to adjust the focal points in nearly every glass slide to achieve optimal results.

The slides were converted into image files with the slide scanner NanoZoomer 2.0-HT (C9600-13) (Hamamatsu Photonics Deutschland GmbH, Herrsching am Ammersee, Germany) producing high-quality scans. Unfortunately, the scanner software did not produce an open image format that we could use. This resulted in the necessity of converting the image files into a format we could utilize. However, in the meantime a set of tools were published to handle the Hamamatsu image format (NDPI) [19,20]. We decided to implement the Zoomify file format.

Image File Storage

Due to the small file size of approximately 20 KB per tile, the slide image data themselves were put into the database since it would be more expensive to open a file handler for each tile than to query the database [19]. However, this yielded a backup problem. A common way to solve this problem is to dump the database at regular intervals and keep the dumps in a safe place. Because of the file size of the image data, the size of these dumps became huge. With the chosen image quality of the slides and slide dimensions, the file sizes in Pate amounted to

approximately 1.5 GB to 2 GB per slide. It would have been inefficient to keep multiple backups of that size which contained mostly redundant data. As the dumps are of a text file nature, a revision control system—GIT 1.8.3.2—was installed to enable dumping of the database regularly, to store the dumps in an efficient manner by accounting only for the differences between revisions, and to permit recovery of backups from any point in time.

Web Design

We commissioned Grüne Kommunikationsdesign, Bodenheim, Germany, for the task of Web design. The goals included design of a streamlined user experience, high usability on both mobile devices and desktops, as well as an appealing graphical interface.

Results

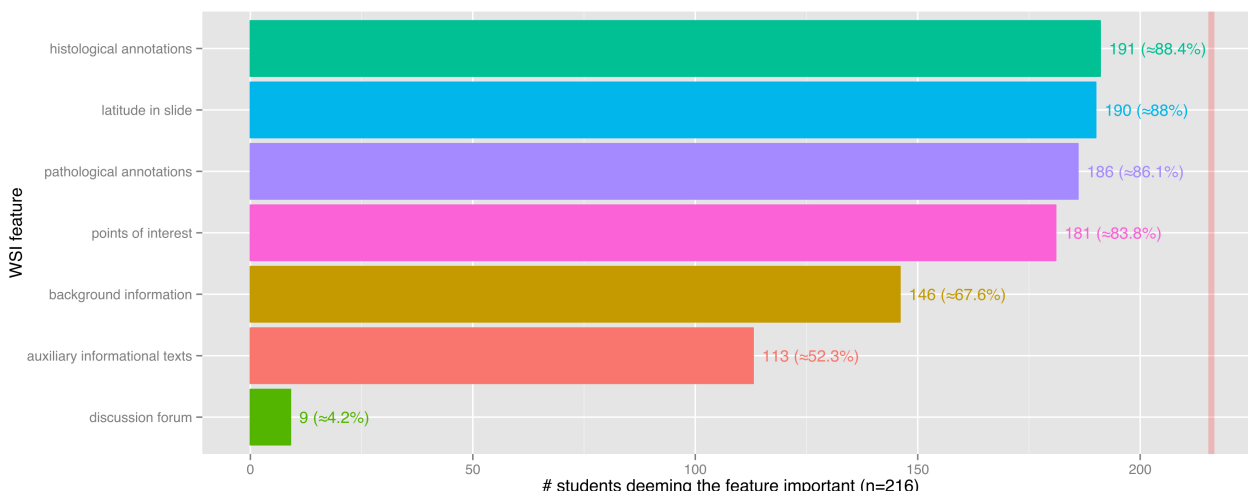
Overview

The Web application, Pate, was developed according to the expectations of medical students. The analysis of the questionnaire revealed that 97.1% (198/204) of the students considered WSI as an important learning tool in the training of histopathological skills. Furthermore, the students assessed WSI as desirable for exam preparation.

Requested Features

A total of 83.8% (181/216) of the students accorded a high priority to points of interest as a prime feature of Pate. Annotations—histological (191/216, 88.4%) and pathological (186/216, 86.1%)—as well as auxiliary informational texts (113/216, 52.3%) were also evaluated positively. In contrast, the deployment of a discussion forum seemed to have little importance for the students, since only 9 out of 216 students (4.2%) recommended this feature. Figure 2 shows graphical results of the importance of WSI application features by students. Furthermore, in the free-field part of the survey, a quiz mode was suggested by the students.

Figure 2. Features for WSI applications in relation to the importance to the students.



Previously Known Whole-Slide Imaging Applications

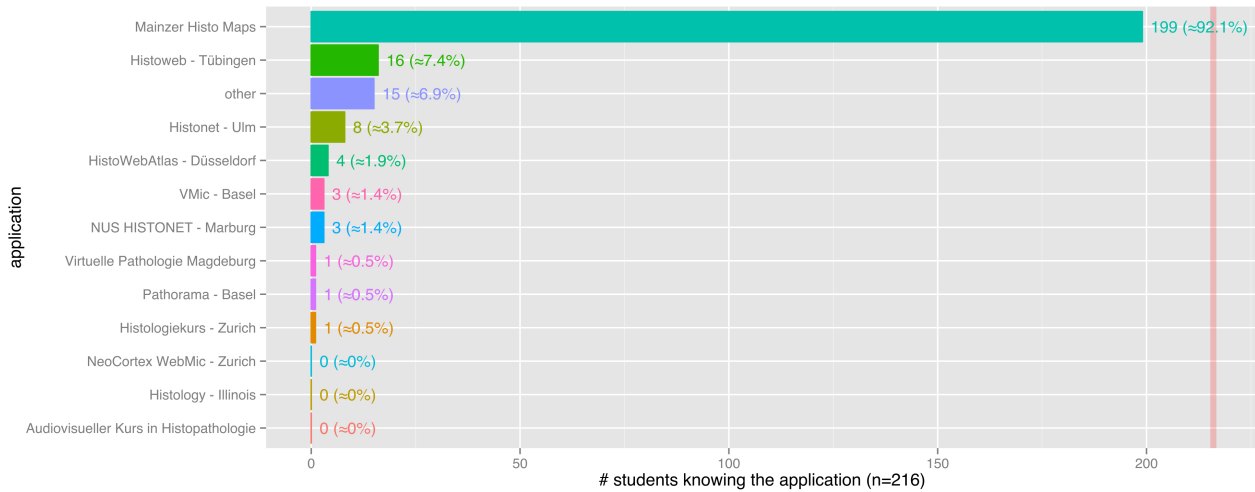
One goal of the survey was to evaluate students' preexisting experiences with other virtual microscopes, including non-WSI

systems. For this purpose, a multiple choice question was included in the survey containing an enumeration of the most known applications. As expected, since all students had already completed a histological course, which propagated this specific

system, most students (199/216, 92.1%) already knew the Mainzer Histo Maps application [4], an online image collection of histological slides of different human organs. The second-most known, the Histoweb Tübingen [20], was less popular (16/216, 7.4%), followed by Histonet Ulm [21] (8/216, 3.7%). All other explicitly listed systems were known by less

than 2% of the students. Of the students, 6.9% (15/216) were familiar with an application which was not listed. NYU Virtual Microscope was not part of the questionnaire since this application was not yet published at the time of our students' survey. Figure 3 shows the graphical results of students' familiarity with WSI applications.

Figure 3. Previously known WSI applications in relation to students' degree of familiarity to these applications.

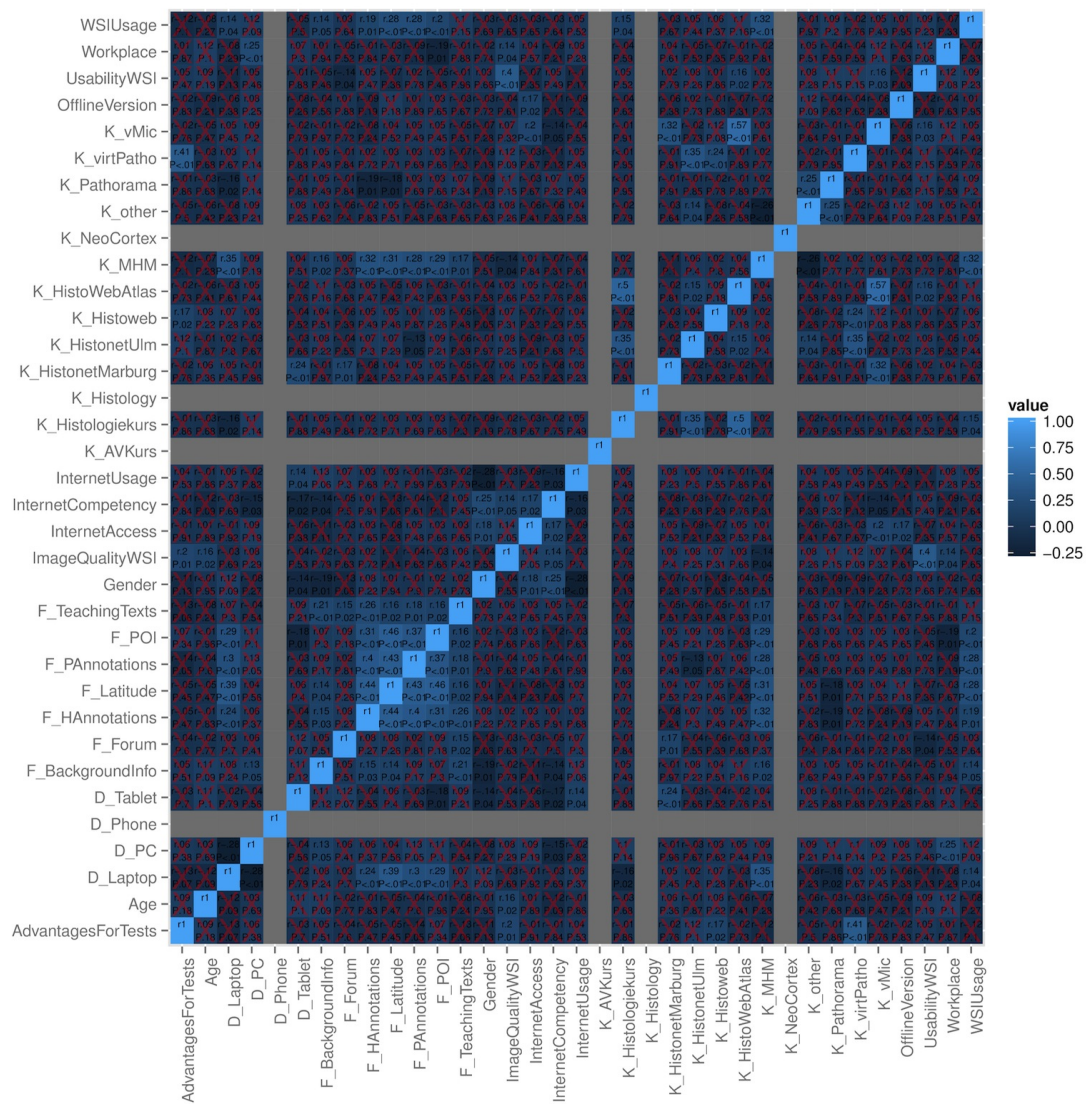


Statistical Correlation and Descriptive Analysis of the Dataset

In order to reveal any correlations in the dataset of the questionnaire, we created a heat map for the Spearman rank correlation coefficient, ρ , or r as in Figure 4, containing every variable of the questionnaire paired with each other. The resulting figure shows all correlation coefficients and P values, where applicable. However, there are some variables where a

correlation is not applicable, as there is no deviation in the dataset. This applies to the variables of two known WSI applications, as well as the usage of a mobile phone as a device to access Pate. Furthermore, most of the correlations are statistically insignificant ($P > .05$). However, some clusters of moderate correlation ($\rho < .6$) remain. For example, there appears to be an association between wanted WSI features, as well as an association between some known WSI applications.

Figure 4. Spearman rank correlation coefficient heat map of the questionnaire items. Each rectangle contains the correlation coefficient in the upper half and the corresponding *P* value in the lower half, if applicable. A red cross marks individual *P* values where *P*<.05. The color of each rectangle indicates the value of the correlation coefficient. The legend below the heat map provides a concise description for each variable.



Variable	Description
InternetAccess	kind of available Internet access
InternetUsage	time spent on the internet
InternetCompetency	self-assessment of internet competency
WSIUsage	how often WSI is used
AdvantagesForTests	is WSI considered helpful in test preparation
Workplace	where WSI is being used
OfflineVersion	demand for an offline version
UsabilityWSI	assessment of usability of WSI applications
ImageQualityWSI	assessment of image quality of WSI applications
Gender	gender of interviewee
Age	age of the interviewee
F_BackgroundInfo	background information
F_Forum	discussion forum
F_Latitude	latitude in slide
F_PAnnotations	pathological annotations
F_POI	points of interest
F_TeachingTexts	auxiliary informational texts

expected features

Variable	Description
K_MHM	Mainzer Histo Maps
K_Histoweb	Histoweb
K_HistonetUlm	Histonet
K_Histology	Histology
K_HistonetMarburg	NUS HISTONET
K_HistoWebAtlas	HistoWebAtlas
K_vMic	vMic
K_Pathorama	Pathorama
K_virtPatho	Virtuelle Pathologie
K_NeoCortex	NeoCortex WebMic
K_AVKurs	Audiovisueller Kurs in Histopathologie
K_Histologiekurs	Histologiekurs
K_other	other, not listed, application
D_PC	PC
D_Laptop	Laptop
D_Phone	Smartphone
D_Tablet	Tablet PC

known WSI applications

device

The New Whole-Slide Imaging Tool, Pate

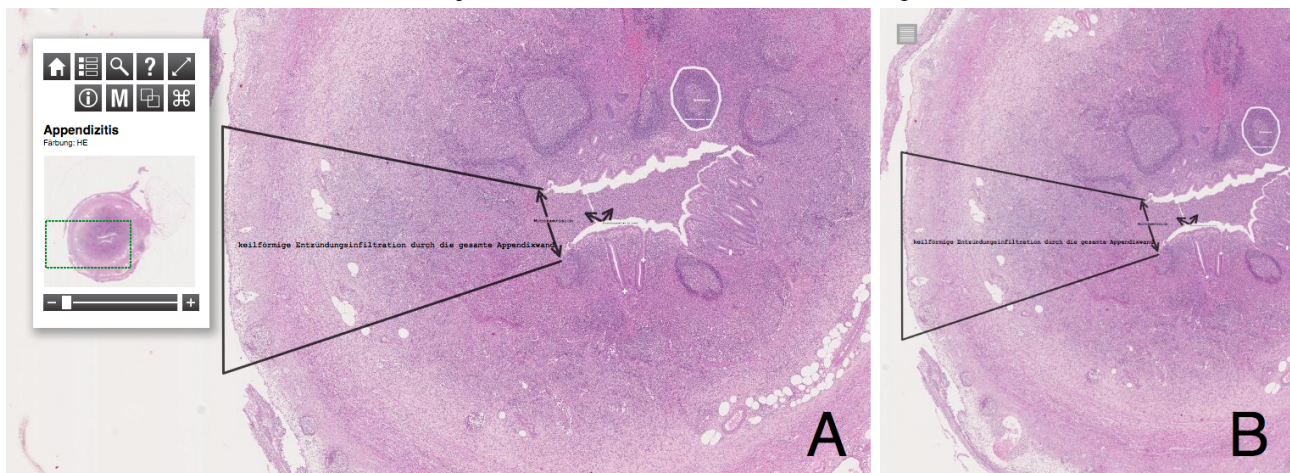
The results of this survey provided the basis for the development of a novel, user-friendly application built using modern Web

technologies, such as HTML5, CSS, and JavaScript. These technologies provide a unified user experience across all major platforms, such as PCs, tablets, and mobile phones. For optimal use, a modern Web browser is recommended.

Pate contains 118 high-quality histopathological specimens from the major human pathological conditions, enriched by several specimens regarding cell-tissue interactions. The slides showing *full-thickness cartilage defect* and *punch-biopsy skin wound* demonstrate the potential benefits of WSI applications also in biomaterial research. These slides are enriched using nondestructive annotations, as well as points of interest. Each slide in Pate can be shared by distributing the URL. This allows

easy sharing of large images as soon as the slides are digitized. Utilizing modern Internet technologies, such as HTML5, CSS, and JavaScript, enables the user to view the image material with a modern Web browser—no proprietary plug-in is required. Pate supports devices with differing screen sizes, such as PCs and mobile phones, by utilizing responsive Web design methods (see [Figure 5](#)).

Figure 5. Side-by-side view of desktop layout (A) versus mobile layout (B) depicting appendicitis (ie, inflammation of the appendix). The control panel folds if the screen resolution is too small (B) to provide an unhindered view on the slide. Pathological annotations are shown.



Performance of Pate

It is hard to determine the actual performance of the image-serving capabilities of Pate. It depends on various factors, such as the performance of the Internet service provider (ISP) of the server, the bandwidth of the ISP offered to the user, and specific routing conditions, among others [22]. Therefore, we chose a test setup which is better controlled by utilizing another computer in the same local area network as the server for testing. This allows us to reduce the influence of poor network performance. We created a list of 50 randomly sampled URLs, addressing 256x256 pixel image tiles, served by the Pate image server. All caching had been disabled. We set up Siege 2.70 (Joe Dog Software) [23], a load-testing and benchmarking tool, in order to simulate high concurrency transactions. One transaction is a complete HTTP request of one randomly sampled URL, the download of the image data, and the closing of the connection. The degree of concurrency determines how many transactions are performed in parallel. When one transaction is finished, the next one is started immediately. For

each concurrency level, one worker is instantiated by Siege. Every worker performs 1000 sequentially executed transactions. For example, a concurrency level of 4 results in 4x1000 transactions, resulting in 4000 transactions. This test was performed for concurrency levels ranging from 1 to 20. The server is powered by a dual-core Intel Xeon E5504 @ 2.00 GHz CPU, 4.6 GB of RAM, and multiple hard drives in a Redundant Array of Independent Disks (RAID) 5 system with a data retrieval capacity of up to 109 MB/s. The results are shown in [Table 2](#) and illustrated in [Figure 6](#).

For a concurrency level of 1, the data show a median response time of 18.8 ms (SD 4.3), while performing 52.6 transactions per second. This translates to a maximum image-serving capability of 3.4 megapixels (MP) per second for a single worker. The overall performance rises up to a concurrency level of 4, resulting in a total of 235.9 transactions per second and 15.4 MP per second while achieving 3.8 MP per connection. Higher concurrency levels do not further boost the performance, but result in overall higher response time and lower individual performance per worker.

Figure 6. Plot of the values of Table 4 depicting the median response time in msec, including the standard deviation, as well as the transactions per second, pixels per second, and total and individual pixels per worker per second.

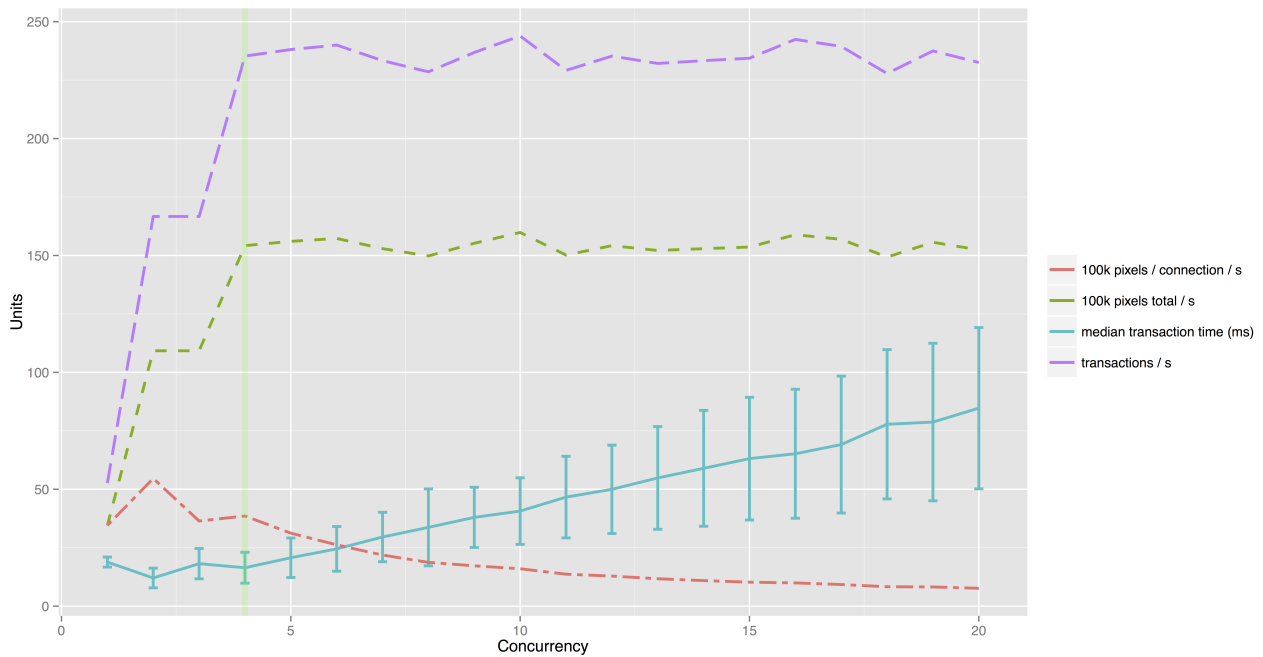


Table 2. Summary of the test setup of Pate.

Concurrency	Total transactions performed, n	Response time (ms), mean (SD)	Transactions/ second, mean	Pixels/ second, mean	Individual transactions/ second/ worker, mean	Individual pixels/ second/ worker, mean
1	1000	18.8 (4.3)	52.6	3,449,263	52.6	3,449,263
2	2000	12.0 (8.4)	166.7	10,922,667	83.3	5,461,333
3	3000	18.2 (13.0)	166.7	10,922,667	55.6	3,640,889
4	4000	16.4 (13.2)	235.3	15,420,235	58.8	3,855,059
5	5000	20.7 (16.9)	238.1	15,603,810	47.6	3,120,762
6	6000	24.5 (19.1)	240.0	15,728,640	40.0	2,621,440
7	7000	29.6 (21.1)	233.3	15,291,733	33.3	2,184,533
8	8000	33.7 (32.9)	228.6	14,979,657	28.6	1,872,457
9	9000	38.0 (25.7)	236.8	15,521,684	26.3	1,724,632
10	10,000	40.7 (28.5)	243.9	15,984,390	24.4	1,598,439
11	11,000	46.6 (34.9)	229.2	15,018,667	20.8	1,365,333
12	12,000	50.0 (37.8)	235.3	15,420,235	19.6	1,285,020
13	13,000	54.8 (43.9)	232.1	15,213,714	17.9	1,170,286
14	14,000	58.9 (49.6)	233.3	15,291,733	16.7	1,092,267
15	15,000	63.1 (52.5)	234.4	15,360,000	15.6	1,024,000
16	16,000	65.2 (55.2)	242.4	15,887,515	15.2	992,970
17	17,000	69.1 (58.6)	239.4	15,691,718	14.1	923,042
18	18,000	77.8 (63.9)	227.9	14,932,253	12.7	829,570
19	19,000	78.7 (67.4)	237.5	15,564,800	12.5	819,200
20	20,000	84.7 (69.0)	232.6	15,240,930	11.6	762,047

Discussion

Principal Findings

The goal of this project was to create a new WSI application for histopathological education according to students' demands and expectations. Therefore, a feature set was extracted from existing WSI applications, including histological and pathological annotations, points of interest, background information, latitude in slide, teaching texts, and a discussion forum. Then, a questionnaire was designed to evaluate the actual needs of medical students, as well as their expectations and their experience with WSI applications. The results of the survey built up the base for a feature set for Pate. From a technical point of view, a further goal of the development was to utilize established Web technologies, such as HTML5 and JavaScript, in order to support as many platforms and devices as possible without the requirement to install any kind of software in advance. In addition, we put an emphasis on supporting mobile platforms with small screens and touch interfaces. This resulted in a unique set of requirements for the development of Pate that was not covered by any other application. During the development, student feedback ensured that the desired features were integrated as was intended by the results of the survey.

With the survey, we identified a high demand regarding a broad feature set for the application, including annotations, POIs, and auxiliary informational texts. We were surprised to learn that, by contrast, the students placed little emphasis on the installation of a discussion forum to permit direct contact with the staff. From the viewpoint of the organizer this facilitates the care of Pate, since a moderation of such a forum is time and personnel consuming. Nevertheless, from the viewpoint of the teacher it would be of interest to establish what problems the students are having in learning histopathological skills. Such a forum could open interesting perspectives to give live information and to react to the needs of the medical students. However, an open forum carries the risk of containing uncontrolled information, as well as incorrect data, which are not useful for an e-learning application. Therefore, the development of a discussion forum was abandoned. A statistical analysis of the survey dataset revealed no further insight besides a correlation of desired WSI features, as well as an association between some known WSI applications.

During deployment of Pate, a scripting language was used, which allowed swift response to the students' demands and offered the implementation of a rapid application development process. By using a professional Web design, a user-friendly and intuitive Web frontend was created. In this context, we focused on supporting mobile devices, as well as conventional desktop computers.

Current limitations of Pate arise mainly as a result of the Zoomify file format used to store digital slides. This format utilizes tiles to limit the data which must be transferred to the client. This leads to approximately 200,000 files for a regular slide. The costs of retrieving a file handle for each file can be reduced by storing the image files in a database. However, storing the image data in the database complicates the backup. Commonly, time-stamped database dumps are used. This would

lead to a volume of data which would be hard to handle. In Pate, this issue was solved by using a version control system. However, creating a backup would be much less difficult without the image files in the database.

One of the design goals of Pate was to support mobile devices. These devices commonly have a slow Internet connection. Because image quality was the first priority when creating the Zoomify tiles, these have a mean size of approximately 20 KB. This can lead to prolonged loading times when using a slow Internet connection.

Finally, the new Web application, Pate, is modeled closely along the expectations of the students by providing a complete set of features, such as points of interest, annotations, and informational texts, which are actually not available as a holistic feature set by other WSI applications.

Perspectives

Follow-Up Survey

As Pate's development has now sufficiently progressed, we will be conducting a follow-up survey, in order to determine if the students' needs have changed and if the implemented feature set has been implemented in a satisfactory way. Furthermore, we will establish a constant feedback loop to be able to respond to new challenges promptly.

Quiz Mode

The survey revealed that many students appreciated a quiz mode. Since Pate was not designed to offer tests of any kind, this feature would have to be implemented from scratch. Pate includes slide image data, meta-information, and regions of interest within each slide. Thus, views of POI regions could be generated, which the students would then be asked to diagnose.

Image Server

The image-serving capabilities of Pate are competitive. The median image retrieval time was measured as 18.8 ms (SD 4.3) while achieving 3.4 MP per second. The peak performance was reached with 15.4 MP per second. This puts Pate in the same performance category as other state-of-the-art image servers [24]. Most of the limitations of Pate were inherited by the Zoomify file format storing prerendered image tiles in a database. A more convenient way to handle large image data would be to archive a single file which can be stored outside the database, while allowing the user to quickly retrieve any section at any magnification. The Tagged Image File Format (TIFF) features storage of pyramidal image data.

Therefore, one future goal is to adapt or to develop an image server that is able to read pyramidal TIFF data server-side and deliver requested image tiles via the Zoomify file format to the client. This method avoids the necessity to redevelop the client and brings the benefit of a file format that supports storing slide image data in one large file. Furthermore, image data could be compressed, according to the current bandwidth, to the client, thus providing a smoother experience for users with small bandwidth, especially users on mobile networks.

Conclusions

According to our survey, students of the University Medical Center Mainz favored a rich feature set, including WSI functionality, POIs, auxiliary informational texts, and annotations. None of the preexisting WSI applications sufficiently fitted in this profile. The feature set could be implemented by relying on rapid application development techniques and open source technologies.

Based on this survey, a new WSI application has been deployed enabling anyone with a device that features a modern Web browser to explore digital slides. This includes mobile phones like Android and iPhone, tablets, desktops, and laptops. On

every platform, a suitable user interface is provided to allow the maximum potential of this tool. This could only be achieved by employing Web technologies that are supported by all modern browsers: JavaScript, HTML5, and CSS. No proprietary plug-ins like Adobe Flash are being used.

Although Pate currently has some issues with the Zoomify file format, it could be shown what Web technologies are capable of providing high-performance WSI experience.

In a future survey, we will analyze whether Pate fits within the expectations of medical students, and we will cross-compare these results with other tools known by the students.

Acknowledgments

We are grateful to Grüne Kommunikationsdesign (Web advisor) for the implementation of the highly appealing and functional Web design.

Conflicts of Interest

None declared.

Multimedia Appendix 1

This ZIP file includes all information regarding the students' survey. This covers the dataset (data.csv) as well as an extensive documentation (survey_statistics.Rmd) and a compiled version (survey_statistics.html).

[[ZIP File \(Zip Archive\), 1MB - ijmr_v4i2e11_app1.zip](#)]

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Abbreviations

CSS: Cascading Style Sheets
HTML5: Hypertext Markup Language 5
ISP: Internet service provider
MP: megapixel
NYUVM: NYU Virtual Microscope
POI: points of interest
RAID: Redundant Array of Independent Disks
TIFF: Tagged Image File Format
WSI: whole-slide imaging

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Original Paper

An Innovative Approach to Informing Research: Gathering Perspectives on Diabetes Care Challenges From an Online Patient Community

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Abstract

Background: Funding agencies and researchers increasingly recognize the importance of patient stakeholder engagement in research. Despite calls for greater patient engagement, few studies have engaged a broad-based online community of patient stakeholders in the early stages of the research development process.

Objective: The objective of our study was to inform a research priority-setting agenda by using a Web-based survey to gather perceptions of important and difficult aspects of diabetes care from patient members of a social networking site-based community.

Methods: Invitations to participate in a Web-based survey were sent by email to members of the PatientsLikeMe online diabetes community. The survey asked both quantitative and qualitative questions addressing individuals' level of difficulty with diabetes care, provider communication, medication management, diet and exercise, and relationships with others. Qualitative responses were analyzed using content analysis.

Results: Of 6219 PatientsLikeMe members with diabetes who were sent survey invitations, 1044 (16.79%) opened the invitation and 320 (5.15% of 6219; 30.65% of 1044) completed the survey within 23 days. Of the 320 respondents, 33 (10.3%) reported having Type 1 diabetes; 107 (33.4%), Type 2 diabetes and taking insulin; and 180 (56.3%), Type 2 diabetes and taking oral agents or controlling their diabetes with lifestyle modifications. Compared to 2005-2010 National Health and Nutrition Examination Survey data for individuals with diabetes, our respondents were younger (mean age 55.8 years, SD 9.9 vs 59.4 years, SE 0.5); less likely to be male (111/320, 34.6% vs 48.4%); and less likely to be a racial or ethnic minority (40/312, 12.8% vs 37.5%). Of 29 potential challenges in diabetes care, 19 were categorized as difficult by 20% or more of respondents. Both quantitative and qualitative results indicated that top patient challenges were lifestyle concerns (diet, physical activity, weight, and stress) and interpersonal concerns (trying not to be a burden to others, getting support from family/friends). In our quantitative analysis, similar concerns were expressed across patient subgroups.

Conclusions: Lifestyle and interpersonal factors were particularly challenging for our online sample of adults with Type 1 or Type 2 diabetes. Our study demonstrates the innovative use of social networking sites and online communities to gather rapid, meaningful, and relevant patient perspectives that can be used to inform the development of research agendas.

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KEYWORDS

social networking; diabetes mellitus; quality of health care; patient centered outcome research

Introduction

Funding agencies and researchers have increasingly recognized the importance of incorporating patient stakeholders into all phases of the research process [1,2]. Patient stakeholder engagement can take place at various points in the “life cycle” of research, including question formulation, study design, interpretation of results, and dissemination of findings [1,3]. The best way to engage patient stakeholders in the research process has not been well defined, and likely depends on the topic under study, the patient population concerned, and the stage of the research process [1,3]. Patient stakeholder engagement can take various forms. For example, patients may act as participants in individual interviews, focus groups, or in-person stakeholder meetings; or as research team collaborators; or may become involved through social networking sites (SNSs) [1,3,4]. In diabetes research, for example, only a few previous studies have described patients’ research priorities and preferences [5-7]. These studies gathered data via focus groups in a single community [6], a questionnaire printed in a German weekly news magazine [5], and a multi-step process including online and paper forms of a survey distributed by a variety of Type 1 diabetes advocacy organizations [7]. Due to time restrictions and resources, most methods of patient stakeholder engagement are limited to using small, highly selective samples [8].

SNSs, which have been growing in popularity, can engage large numbers of thoughtful patient stakeholders about a range of health and research topics, and can do so more quickly and at lower cost than traditional survey methods [8,9]. PatientsLikeMe is one such health- and disease-related SNS that has more than 190,000 members internationally. It offers patients tools to track their illness, share health data with peers, and participate in research studies [10]. PatientsLikeMe has established a level of trust among its users, which is an important component of stakeholder engagement [8,11]. Researchers using PatientsLikeMe have published more than 30 peer-reviewed publications [12] focusing on conditions such as amyotrophic lateral sclerosis [13-15], Parkinson’s disease [10,13,16], multiple sclerosis [17], epilepsy [18], mood disorders [13], and organ transplantation [19].

The SUPREME-DM (SURveillance, PREvention, and ManagEMENT of Diabetes Mellitus) network is a consortium of 11 member organizations of the HMO Research Network [20,21]. Research institutes embedded in these health systems have developed the largest and most clinically-detailed cohort of privately-insured patients with diabetes in the United States (the *DataLink*) [22]. The SUPREME-2 (SUPREME-DM: Sustaining a Learning Research Network) study was funded by

the Agency for Healthcare Research and Quality in 2013, with the goal of enhancing the capacity of the SUPREME-DM *DataLink* to address the research priorities of patient stakeholders [23]. Over a 12-month period, we used a systems-based participatory research approach to engage stakeholders. This included a one-day stakeholder meeting held in Washington, DC in 2014, followed by a webinar virtual meeting [23,24]. Stakeholders included patients, researchers, and leaders of health care delivery systems, federal agencies, membership/advocacy groups, and disadvantaged populations. However, we wanted to ensure that the voices of diabetes patients figured prominently in our stakeholder engagement process. Given time and resource constraints, the PatientsLikeMe online diabetes community provided an opportunity to engage with a geographically-diverse, thoughtful, and interested group of individuals with diabetes. This population rapidly provided qualitative and quantitative patient perspectives that informed and supplemented the research preferences and priorities that were identified during the in-person and virtual stakeholder engagement processes.

The overall purpose of our online survey was to obtain research preferences and priorities from an interested group of individuals with diabetes that could be used to help guide subsequent SUPREME-DM stakeholder engagement and research priorities. Our specific research aims were (1) to identify issues in diabetes management that PatientsLikeMe patient stakeholders find difficult or important in the following domains: accessing diabetes care, communication with providers, medication management, lifestyle behaviors, and personal relationships; (2) to gather an array of patient perspectives that would inform, amplify, and supplement the findings from the in-person stakeholder meeting; and (3) to assess the pragmatic usefulness of online surveys for conducting diabetes research among an SNS population.

Methods

The SUPREME-DM Network

The SUPREME-DM network was funded by the Agency for Healthcare Research and Quality (R01HS019859) in 2010 [20,21]. SUPREME-DM is a consortium of 11 US integrated health systems. Research institutes embedded within these health systems have developed a distributed virtual data warehouse that contains the following types of anonymous de-identified information gathered from their electronic health record and administrative data systems: demographic characteristics, outpatient pharmacy dispensing details, laboratory tests and associated results, and diagnosis and procedure codes from outpatient and inpatient health care encounters [25]. The resulting diabetes *DataLink* has been used in research on

diabetes surveillance and comparative effectiveness, and includes information collected from 2005 onward for approximately 16 million adults and 2.5 million children in 10 states [21]. A subsequent study, the SUPREME-2 study, was funded by the Agency for Healthcare Research and Quality (1R01HS022963-01) in 2013, with the goal of enhancing the capacity of the SUPREME-DM DataLink to address the research priorities of patient and organizational stakeholders [23].

Survey Design and Implementation

To rapidly obtain input from patient stakeholders, we conducted an online survey with the PatientsLikeMe diabetes community (see [Multimedia Appendix 1](#)). Because individuals in the PatientsLikeMe network have volunteered to share personal information for surveys such as ours, and because we did not collect any identifying information, this survey was not considered human subjects research by the Kaiser Permanente Colorado Institutional Review Board. No incentives were provided to participants.

The survey was developed by SUPREME-DM investigators in collaboration with PatientsLikeMe staff. The survey was pilot tested by 50 PatientsLikeMe members, and modified based on their responses. The final survey is provided in [Multimedia Appendix 1](#). The survey included several questions modified from the National Health and Nutrition Examination Surveys (NHANES) and the Behavioral Risk Factor Surveillance Surveys (BRFSS). The modified questions were related to age, race, ethnicity, gender, type of diabetes, duration of diabetes, general health status, primary activity, types of medication, diabetes complications, weight, and height [26,27]. The remainder of the survey used 29 items to assess patient experience with and challenges in diabetes care, provider communication, medication management, and other topics (eg, lifestyle behaviors and personal relationships). Each topic domain was preceded by the prompt, “We want to hear which questions about [domain heading] are most important to you right now. Please tell us which of these concerns about diabetes impacts you personally, and how difficult each one makes your life.” The five response options were: not difficult, a little difficult, somewhat difficult, very difficult, and does not apply. There were also three global, open-ended questions: (1) “Are there any other challenges or concerns about your diabetes care that you want us to know?”, (2) “Thinking about when you were first told you had diabetes, what was or would have been most helpful for you to know about your diabetes at that time?”, and (3) “Thinking about 3-5 years into the future from now, what do you feel will be important to learn or know about your diabetes? Why?”

Using the PatientsLikeMe *Private Message* tool, we sent invitations to the individual email accounts of eligible PatientLikeMe members from the diabetes community. The invitation encouraged those participants to log in to their PatientsLikeMe account and complete the Web-based survey. Inclusion criteria were: self-reported Type 1 or Type 2 diabetes, aged 18 years or older, resident of the United States, and email contact from PatientsLikeMe Private Messages enabled. We also required participants to be active participants in PatientsLikeMe. We defined ‘active’ as any activity during the past 360 days for those with Type 1 diabetes, and 3 or more

log-ins during the past 90 days for those with Type 2 diabetes. We sent the invitation to individuals with unknown ages or locations of residence, but if they indicated on their survey that they were younger than 18 years or lived outside the United States, then their responses were discarded. The survey was open for 23 days (2014 Jan 15 through 2014 Feb 6), and reminder emails were sent at 3 days and 14 days after the initial invitation. Participants could complete the survey over several sessions if they desired.

Analysis

If participants did not reach the end of the survey, then their responses were not analyzed. We calculated the mean and standard deviation for continuous variables and percentage for categorical variables. Body mass index (BMI) was categorized as normal ($BMI < 25.0 \text{ kg/m}^2$), overweight ($BMI = 25.0-29.9 \text{ kg/m}^2$), Class I obese ($BMI = 30.0-34.9 \text{ kg/m}^2$), and Class II obese or higher ($BMI \geq 35.0 \text{ kg/m}^2$). To report measures of patient experience, we combined the percentages of individuals responding “somewhat difficult” or “very difficult”, and removed from the denominator individuals who indicated “does not apply.” We compared results by diabetes type and insulin status (Type 1 diabetes, Type 2 diabetes taking insulin, and Type 2 diabetes not taking insulin); gender; age; general health status; depression; and primary activity. For significance testing, we used two-sided Fisher Exact tests for categorical variables and Kruskal-Wallis tests for continuous variables. However, as this was an exploratory analysis of a convenience sample, we did not primarily rely upon statistical significance testing, but instead looked for magnitude of the response, meaningful differences in percentages, and/or relative rankings.

To examine the three qualitative, open-ended measures, we used a content analysis approach to provide an overview of the major themes emerging from each question [28-30]. In an effort to keep the open-ended comments grounded in the experiences of respondents, analysis was conducted by an objective investigator (JLS) with expertise in qualitative analyses who was not aware of the closed-ended survey results. An initial reading of open-ended responses to understand the general participant response and context to each specific question was followed by a second reading to summarize content. For example, if a participant wrote “I wished a doctor had told me to take diabetes more seriously earlier on...,” then this was summarized as “take more seriously.” Upon a third reading of the open-ended responses, summary phrases were condensed into themes, but with enough detail to preserve their intended meaning. We then tabulated the frequencies with which these themes were expressed. When possible, themes were aggregated into summary themes. Responses could reflect a single or multiple themes. The themes were then shared with the study team for comment and consensus. In this paper, we provide the list of these themes and the frequency of text responses for each theme mentioned.

Results

Respondent Characteristics

Of the 6219 PatientsLikeMe members with diabetes who were invited to participate, 1044 (16.79%) opened the invitation. Of those who opened the invitation, 188 opted out, 273 did not start the survey, 194 started but did not complete the survey, and 389 completed the survey. Of the 389 who completed the survey, 69 were excluded because they resided outside of the United States, leaving a final sample size of 320 (5.15% of 6219; 30.65% of 1044). Compared to the 5899 who were not included in the analysis, the 320 complete responders were older (mean age 55.8 years, SD 9.9 vs 53.7 years, SD 11.3, $P < .001$); more likely to have Type 1 diabetes (33/320, 10.3% vs 419/5899, 7.10%, $P = .04$); and possibly more likely to be female (209/320, 65.3% vs 3563/5899, 60.40%, $P = .09$).

Of the 320 respondents, 33 (10.3%) had Type 1 diabetes, 107 (33.4%) had Type 2 diabetes and were taking insulin, and 180 (56.3%) had Type 2 diabetes and were on oral agents (but not insulin) or controlled their diabetes with lifestyle interventions alone. Individuals with Type 1 diabetes were younger than those with Type 2 diabetes, had a lower BMI, longer duration of diabetes, were more likely to be employed, and reported better overall general health than individuals with Type 2 diabetes (Table 1). Rates of self-reported diabetes complications and comorbidities were high, and except for kidney disease and retinopathy, tended to be higher among individuals with Type 2 diabetes than among individuals with Type 1 diabetes (Table 1). Compared to the NHANES 2005-2010 diabetes population, our sample had a higher percentage of females, more non-Hispanic whites, and a smaller proportion of individuals aged 65 years or older [31] (Table 1).

Table 1. Characteristics of PatientsLikeMe survey respondents (n=320).

	Full cohort	Type 1 diabetes	Type 2 diabetes taking insulin	Type 2 diabetes not taking insulin	P value ^a	NHANES ^b 2005-2010 [31]
	n (%) or mean (SD)	n (%) or mean (SD)	n (%) or mean (SD)	n (%) or mean (SD)		
Female, n (%)	209/320 (65.3)	22/33 (66.7)	65/107 (60.8)	122/180 (67.8)	.49	51.6
Race/ethnicity, n (%)						
Non-Hispanic white	272/312 (87.2)	28/32 (87.5)	88/102 (82.4)	160/178 (89.9)	.14	62.5
Non-Hispanic black	17/312 (5.5)	0/32 (0.0)	9/102 (8.8)	8/178 (4.5)		16.7
Other	23/312 (7.4)	4/32 (12.5)	9/102 (8.8)	10/178 (5.6)		20.8
Age, n (%) or years, mean (SD)						
Years, mean (SD)	55.8 (9.9)	47.7 (12.9)	57.1 (9.0)	56.5 (9.1)	<.001	59.4
< 55 years, n (%)	130/320 (40.6)	21/33 (63.6)	37/107 (34.6)	72/180 (40.0)	.03	60.5
55-64 years, n (%)	136/320 (42.5)	11/33 (33.3)	50/107 (46.7)	75/180 (41.7)		
> 65 years, n (%)	54/320 (16.9)	1/33 (3.0)	20/107 (18.7)	33/180 (18.3)		39.5
Body mass index, n (%) or kg/m², mean (SD)						
kg/m ² , mean (SD)	33.9 (8.3)	26.9 (5.0)	36.2 (8.4)	33.9 (8.1)	<.001	32.8
< 25.0 kg/m ² , n (%)	45/318 (14.2)	16/33 (48.5)	8/105 (7.6)	21/180 (11.7)	<.001	12.9
25.0-29.9 kg/m ² , n (%)	66/318 (20.8)	6/33 (18.2)	19/105 (18.1)	41/180 (22.8)		25.9
30.0-34.9 kg/m ² , n (%)	80/318 (25.2)	8/33 (24.2)	20/105 (19.1)	52/180 (28.9)		
≥35.0 kg/m ² , n (%)	127/318 (39.9)	3/33 (9.1)	58/105 (55.2)	66/180 (36.7)		61.2
Duration of diabetes, n (%) or years, mean (SD)						
Years, mean (SD)	12.1 (11.4)	28.0 (15.2)	12.9 (9.2)	8.7 (9.0)	<.001	
0-5 years, n (%)	108/320 (33.8)	3/33 (9.1)	22/107 (20.6)	83/180 (46.1)	<.001	
5-10 years, n (%)	78/320 (24.4)	4/33 (12.1)	31/107 (29.0)	43/180 (23.9)		
> 10 years, n (%)	134/320 (41.9)	26/33 (78.8)	54/107 (50.5)	54/180 (30.0)		
Education, n (%)						
Some high school	1/319 (0.3)	0/33 (0.0)	0/106 (0.0)	1/180 (0.6)	.26	
High school graduate	56/319 (17.6)	3/33 (9.1)	19/106 (17.9)	34/180 (18.9)		
Some college	136/319 (42.6)	10/33 (30.3)	43/106 (40.6)	83/180 (46.1)		
College graduate	81/319 (25.4)	12/33 (36.4)	28/106 (26.4)	41/180 (22.8)		
Post graduate	45/319 (14.1)	8/33 (24.2)	16/106 (15.1)	21/180 (11.7)		
Primary activity, n (%)						
Employed	109/320 (34.1)	19/33 (57.6)	25/107 (23.4)	65/180 (36.1)	.001	
Homemaker	16/320 (5.0)	3/33 (9.1)	4/107 (3.7)	9/180 (5.0)		
Student	5/320 (1.6)	1/33 (3.0)	3/107 (2.8)	1/180 (0.6)		
Out of work	17/320 (5.3)	3/33 (9.1)	8/107 (7.5)	6/180 (3.3)		
Unable to work	91/320 (28.4)	5/33 (15.2)	37/107 (34.6)	49/180 (27.2)		
Retired	82/320 (25.6)	2/33 (6.1)	30/107 (28.0)	50/180 (27.8)		
General health, n (%)						
Excellent	7/318 (2.2)	2/33 (6.1)	1/106 (0.9)	4/179 (2.2)	.007	
Very good	48/318 (15.1)	12/33 (36.4)	10/106 (9.4)	26/179 (14.5)		
Good	109/318 (34.3)	6/33 (18.2)	35/106 (33.0)	68/179 (38.0)		

	Full cohort	Type 1 diabetes	Type 2 diabetes taking insulin	Type 2 diabetes not taking insulin	P value ^a	NHANES ^b 2005-2010 [31]
	n (%) or mean (SD)	n (%) or mean (SD)	n (%) or mean (SD)	n (%) or mean (SD)		
Fair	94/318 (29.6)	9/33 (27.3)	33/106 (31.1)	52/179 (29.1)		
Poor	60/318 (18.9)	4/33 (12.1)	27/106 (25.5)	29/179 (16.2)		
Complications, n (%)						
High blood pressure	227/318 (71.4)	15/33 (45.5)	88/106 (83.0)	124/179 (69.3)	<.001	
High cholesterol	243/312 (77.9)	17/32 (53.1)	86/104 (82.7)	140/176 (79.6)	.003	
Depression	189/315 (60.0)	18/33 (54.6)	64/106 (60.4)	107/176 (60.8)	.79	
Heart attack	27/315 (8.6)	0/33 (0.0)	18/105 (17.1)	9/177 (5.1)	<.001	
Heart disease	50/315 (15.9)	6/33 (18.2)	27/105 (25.7)	17/177 (9.6)	.001	
Stroke	22/312 (7.1)	2/33 (6.1)	10/103 (9.7)	10/176 (5.7)	.46	
Kidney disease	28/310 (9.0)	4/33 (12.1)	15/101 (14.9)	9/176 (5.1)	.02	
Retinopathy	66/305 (21.6)	12/31 (38.7)	33/104 (31.7)	21/170 (12.4)	<.001	
Neuropathy	148/304 (48.7)	13/33 (39.4)	67/103 (65.1)	68/168 (40.5)	<.001	
Extremity ulcers	49/313 (15.7)	5/33 (15.2)	22/103 (21.4)	22/177 (12.4)	.14	

^aA 3-way comparison of Type 1 diabetes, Type 2 diabetes taking insulin, and Type 2 diabetes not taking insulin.

^bNational Health and Nutrition Examination Surveys.

Quantitative Findings

Table 2 shows the topics that were found “somewhat difficult” or “very difficult” by 20% or more of respondents. The full survey, with all 29 topics, is found in [Multimedia Appendix 1](#). Respondents most often identified difficulties in the Diet and Exercise domain, with between 50.5% and 66.1% citing all four topics in this domain as difficult. All topics in the Relationships With Others domain were also found difficult by 25.3%-38.0% of respondents. Individuals also indicated high levels of difficulty with “paying for my diabetes visits, treatment, or supplies;” “seeing specialty providers such as endocrinologists, diabetes educators, dietitians, etc;” “testing my blood sugars;” “managing side effects of interactions between my medications;” “using alternative medicine;” and a number of the topics within the Communication domain.

In subgroup analysis, individuals with Type 1 diabetes generally reported lower levels of difficulty than did individuals with Type 2 diabetes (see [Multimedia Appendix 2](#)). Exceptions (where the percentage of individuals with Type 1 diabetes reporting difficulty with a topic was at least 5% higher than that of individuals with Type 2 diabetes) included some topics in the Getting Diabetes Care and Communication domains, as well as “managing side effects of interactions between my

medications,” and “trying not to be a burden to others.” Individuals with Type 2 diabetes who were taking insulin nearly uniformly reported higher levels of difficulty for all domains than those with Type 2 diabetes who were treated only with oral agents or lifestyle modification. Diet and Exercise topics were identified as most difficult for both groups, and both groups mainly ranked these topics similarly (see [Multimedia Appendix 2](#)).

Subgroup analyses by gender, age (< 55 years vs >55 years), and duration of diabetes showed minimal differences (data not shown). Women were more likely than men to report difficulty with “feeling that my doctor respects, understands, and listens to me” (52/206, 25.2% vs 17/108, 15.7%), “testing my blood sugars” (64/201, 31.8% vs 21/107, 19.6%), “getting enough physical activity” (151/208, 72.6% vs 60/111, 54.1%), “managing my weight” (152/208, 73.1% vs 52/111, 46.8%), and “managing stress” (129/207, 62.3% vs 49/110, 44.6%). Frequencies of difficulty in most domains were greater among individuals reporting fair or poor health compared to those reporting excellent, very good, or good health; individuals with depression compared to those without depression; and individuals whose primary activity was “unable to work” or “other” compared to those whose primary activity was “retired” or “employed” (data not shown).

Table 2. Survey domains for which at least 20% of participants responded “very difficult” or “difficult” (n=320).

Domain	Topic	n (%)
Getting diabetes care		
	Paying for my diabetes visits, treatment, or supplies	106/307 (34.5)
	Seeing specialty providers such as endocrinologists, diabetes educators, dieticians, etc	83/291 (28.5)
Communication		
	Using e-mail, texting, or the Web to reach my health care provider	68/231 (29.4)
	Making sure that all my diabetes care providers are working together for me	77/298 (25.8)
	Making choices about diabetes medicine and other treatments that I think are best for me	76/301 (25.2)
	Feeling that my doctor or other health care providers respect, understand, and listen to me	69/314 (22.0)
	Working with my doctor to set personal goals for my treatment	66/309 (21.4)
Medications		
	Testing my blood sugars	85/308 (27.6)
	Managing side effects of interactions between my medications	76/275 (27.6)
	Using alternative medicine (natural herbs, acupuncture, meditation, etc)	43/163 (26.4)
Diet and exercise		
	Getting enough physical activity	211/319 (66.1)
	Managing my weight	204/319 (64.0)
	Managing stress	178/317 (56.2)
	Eating a healthy diet	161/319 (50.5)
Relationships with others		
	Trying not to be a burden to others	112/295 (38.0)
	Getting enough support from my family and friends	117/317 (37.0)
	Diabetes interfering with my work	51/194 (26.3)
	Diabetes interfering with my social activities with family, friends, neighbors, or groups	71/281 (25.3)

Qualitative Findings

The open-ended survey questions elicited numerous responses (259-299 responses to each of the three questions). Summary themes for 2 of the 3 questions are shown in [Tables 3 and 4](#), and illustrative quotes for all three questions are shown in [Multimedia Appendices 3-5](#). Summary themes included: educational needs (more instruction about healthy lifestyle behaviors, diabetes as a disease, diabetes care management, and

taking medications); the need for shared decision-making and compassionate support; care access concerns (such as referral issues and costs); participants’ desires to know more about disease progression, new treatments and technologies, long-term care and lifestyle management options, and possibilities for reversing or curing diabetes; and the challenges of managing comorbid conditions (such as depression, rheumatoid arthritis, fibromyalgia, and heart disease).

Table 3. Summary themes for responses to the question, “Thinking about when you were first told you had diabetes, what was or would have been most helpful for you to know about your diabetes at that time?” (n=299).^a

Summary theme	Theme	n
Lifestyle education		90
	Education in diet, carbohydrate consumption, and food preparation	49
	Clear, realistic assessment of lifestyle goals to work on (diet, exercise, smoking, etc)	16
	Education and support in weight loss (ie, gyms, classes, bariatric surgery)	15
	Education on importance of active lifestyle and ongoing exercise routine	7
	Encouragement to avoid stress and stay calm and relaxed	3
Shared decision making, compassion, reassurance, and support		87
	Realistic discussion with provider about the seriousness of diabetes, that it requires diligent and daily self-care and treatment, and that it can be managed	28
	At time of diagnosis, support in dealing with denial or overwhelming fear of diabetes	16
	Hope and reassurance that a person with diabetes progression can be slowed, possibly reversed, and that a person can live a normal and good life	16
	Open, two-way discussion with provider on all aspects of diabetes and treatment options	13
	Credible, helpful resources: information on diabetes (books, web, literature) and also social support groups	10
	Compassion from provider with no blaming or shaming of person trying to manage their diabetes	4
Education on the disease of diabetes		86
	Education in diabetes progression, long-term consequences, side effects, and symptoms of worsening	39
	Education on what diabetes is, its causes, and contributing factors	20
	Clear explanation of blood sugars, A1c levels, and insulin resistance	8
	Education on diabetes interactions and impacts on comorbid conditions (depression, hypothyroidism, kidney disease, hypoglycemia)	9
	Awareness and education about transitioning from prediabetes to diabetes	6
	Awareness and education about pregnancy and diabetes, including gestational diabetes	4
Diabetes care management education		36
	Education on the importance and reason for routinely self-monitoring blood glucose levels	13
	Stronger emphasis/education that diabetes can be managed and treated well with diet, lifestyle, and medications	23
Care access, referrals, and costs		24
	Timely access/referrals to specialists (ie, endocrinologists), dietitians, and diabetes educators/classes at time of diagnosis and as part of ongoing care	17
	Timely access to medications and durable equipment (i.e. insulin pump)	4
	Realistic appraisal of immediate and long-term diabetes financial impact (ie, provider costs, medications, blood glucose monitors, test strips)	3
Education about diabetes medications		23
	Clear explanations about medication side-effects (eg, digestive, impotence, weight gain) and alternative medication options	10
	Understanding of how medications are processed by the body, including the time at which they are taken	8
	Education of non-pharmaceutical alternatives or providers	5

^aBecause an individual’s response could reflect multiple themes, the total number of n values for the themes is greater than the total number of respondents (n=299). The n value for a summary theme is the sum of the n values for the individual themes within that category.

Table 4. Summary themes for responses to the question, “Thinking about 3-5 years into the future from now, what do you feel will be important to learn or know about your diabetes? Why?” (n=283).^a

Summary theme	Theme	n
Understand disease progression		120
	Progression and impact on overall health and aging	60
	Progression and impact on specific organ systems (ie, eyes, kidneys, heart, depression, neuropathy, etc)	60
Long-term control, treatment, and care management strategies		106
	How to effectively maintain and manage blood sugars over the years	54
	How to avoid or best manage medication use, especially insulin use	19
	How to manage neuropathy, its associated pain, and prevent amputations	15
	How to have an ongoing individualized, personalized, and integrated care management plan	10
	How to continue to care for diabetes and know as much as possible about it over the years	8
Awareness of new treatments and technologies		72
	Current science, research, and technology for new ways to treat and manage diabetes	36
	Information on: new medications, new glucose management technologies, improved diet/lifestyle options	36
Long-term lifestyle management strategies		43
	Knowing more about healthy eating, nutrition, and access to proper foods over the years	32
	Having an exercise routine tailored to a person’s lifestyle and physical limitations as years progress	11
Managing future costs		40
	How to manage and afford ongoing costs of medications, test supplies, foods, exercise fees, etc	20
	How to manage and afford any increase in costs of medications, test supplies, foods, exercise fees, etc	20
Reverse or cure diabetes		37
	Strongly desire a cure be found	28
	Desire to know how to reverse diabetes, including use of bariatric surgery	9
Managing overall health and well-being		23
	How to live longer, healthier, happier, and better with diabetes	16
	How to accept living with diabetes and the need for lifestyle changes	7

^aBecause an individual’s response could reflect multiple themes, the total number of n values for the themes is greater than the total number of respondents (n=283). The n value for a summary theme is the sum of the n values for the individual themes within that category.

Discussion

Principal Findings

Our findings illustrate that administering a survey using SNSs and online communities is feasible, and can rapidly generate rich sets of quantitative and qualitative data that may be used to inform research priorities. In this study, we reached over 1000 potential participants with diabetes and completed our data collection in just 23 days.

Over the past two decades, many studies have explored the underlying barriers to and facilitators of diabetes care delivery, self-management, and education from the patient’s perspective [32-38]. Our findings generally agree with previous studies, and provide some assurance that SNSs and their associated online communities do generate important insights about patients’ needs that may inform future research. At the same

time, these communities offer a setting that facilitates the efficient and rapid collection of patient input and perspectives. The open-ended responses analyzed in this study provided a particularly large and rich set of qualitative data that compare favorably to the types of information generally obtained through in-person focus groups or individual interviews.

We felt it was important to collect information about patients’ concerns for the future, as this is the perspective that motivates many research agendas. We acknowledge that individuals generally have difficulty predicting preferences for future states, and thus, that participants may have had problems accurately addressing this question [39]. However, since our population included people along the diabetes continuum (from recently diagnosed diabetes to long standing diabetes with multiple complications), we believe that we were able to adequately

capture individuals' perspectives throughout the diabetes life cycle.

Our survey was motivated by the desire to inform the development of an ongoing research agenda for the SUPREME-DM network. Only a few previous studies have described patients' research priorities and preferences related to diabetes, and these were limited in scope and/or participation [5-7]. One study used a questionnaire printed in a German weekly news magazine in order to prioritize nine broad research topics ("development, pathophysiology and prevention of diabetes," "transplantation and cell therapy," etc) [5]. Another study described a series of six focus groups in a single community that involved a total of 39 adults with diabetes [6]. A third study used a multi-step process that included online and paper forms of a survey distributed by diabetes advocacy organizations, but its focus was limited to research priorities for Type 1 diabetes [7]. In choosing the best method to establish patients' research priorities and preferences, which is a crucial task in patient engagement, researchers need to weigh a variety of competing interests that include timeframe, budget, size and representativeness of the patient sample, and desired depth of responses (qualitative vs quantitative) [4,40]. The benefits of our SNS-based approach included short timeframe, large patient sample, and depth of responses.

Well-recognized limitations of online surveys based on SNSs include selection bias due to the potential unrepresentativeness of the members of these communities, and low response rates [17]. In addition, items such as age, weight, type of diabetes, and comorbidities are self-reported, which is a problem shared with other online surveys and population-based surveys such as BRFSS and components of NHANES.

Compared to the 2005-2010 NHANES sample of individuals with self-reported diabetes, our sample differed in a number of important demographic characteristics [31]. This raises concerns that the difficulties expressed by our sample may not be representative of those most prevalent within the broader diabetes community. Given that, in our sample, the levels of self-reported comorbidities (including depression) were high and self-reported overall health status was low, we suspect that the sample included an overrepresentation of individuals with more severe diabetes [41]. Previous research in other PatientsLikeMe communities has found that the PatientsLikeMe population tends to have a higher proportion of females [19], non-Hispanic whites [19], more educated individuals [17], and younger adults [16,17], relative to an external comparator population with the same disease condition. We confirmed these findings by comparing our data to 2005-2010 NHANES data for individuals with diabetes.

We received complete responses from only 5.15% (320/6219) of individuals who were invited to participate. Part of this stems from the difficulty of identifying active users of the SNS. Only 16.79% (1044/6219) of individuals who were sent invitations to participate in the survey actually opened them. Of those who opened the invitation, we received complete responses from 37.26% (389/1044), of whom we subsequently excluded 6.61% (69/1044) who did not meet the eligibility criterion of US residence, for a final response rate of 30.65% (320/1044). Expected response rates for these types of online survey have not been well described, but were between 9% and 36% for previous PatientsLikeMe surveys [42-44]. Individuals responding to our survey represent those who are most active on an online SNS, and therefore are different from the general population with diabetes in many important ways, including level of engagement in their health care, access to technology, available time to participate in these communities, and level of education. Thus, our findings cannot be extrapolated to the broader population of individuals with diabetes.

Despite these limitations, the approach to patient engagement we describe here had a number of strengths [17]. First, it was easy to identify individuals who were interested and engaged in participating. Second, we were able to collect information from a relatively large number of patient stakeholders in very little time (23 days of survey availability, and a total of 93 days from initial planning to survey close, including 14 days of planned downtime due to holidays). Third, we were able to collect a wealth of qualitative data, only a small sample of which has been included in this manuscript. Fourth, this was a very cost-effective approach. Fifth, participants expressed gratitude for being given the opportunities to participate in research that was important to them and to share their stories and feedback via the open-ended measures. One potential verification strategy would be to circulate the results back to the original survey sample and ask for agreement or disagreement with these, or for further interpretation of the data. We did subsequently present these results to patient stakeholders at an in-person meeting, and found that those patients' diabetes care experiences resonated well with those articulated by PatientsLikeMe respondents.

Conclusions

Lifestyle and interpersonal factors were of particular concern to our online sample of adults with diabetes and, overall, difficulties associated with care for the condition were similar for adults with Type 1 or Type 2 diabetes. Our experience shows that SNSs and online communities can be accessed to quickly gain meaningful and relevant patient perspectives that can help inform the development of a research agenda.

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Conflicts of Interest

Marcy Fitz-Randolph is an employee of PatientsLikeMe and owns stock options in the company. The PatientsLikeMe Research and Development team received research funding (including conference support and consulting fees) from Abbvie, Accordia, Actelion, Amgen, AstraZeneca, Avanir, Biogen, Boehringer Ingelheim, Genzyme, Janssen, Johnson & Johnson, Merck, Novartis, Sanofi, and UCB. Other authors declare no conflicts of interest.

Multimedia Appendix 1

PatientsLikeMe online diabetes survey.

[[PDF File \(Adobe PDF File\), 106KB - ijmr_v4i2e13_app1.pdf](#)]

Multimedia Appendix 2

Percentage of participants responding “very difficult” or “difficult” for each domain, by type of diabetes and insulin status (n=320).

[[PDF File \(Adobe PDF File\), 95KB - ijmr_v4i2e13_app2.pdf](#)]

Multimedia Appendix 3

Summary of responses to the question, “Thinking about when you were first told you had diabetes, what was or would have been most helpful for you to know about your diabetes at that time?” (n=299).

[[PDF File \(Adobe PDF File\), 94KB - ijmr_v4i2e13_app3.pdf](#)]

Multimedia Appendix 4

Summary of responses to the question, “Thinking about 3-5 years into the future from now, what do you feel will be important to learn or know about your diabetes? Why?” (n=283).

[[PDF File \(Adobe PDF File\), 85KB - ijmr_v4i2e13_app4.pdf](#)]

Multimedia Appendix 5

Summary of responses to the question, “Are there any other challenges about your diabetes care that you want us to know?” (n=257).

[[PDF File \(Adobe PDF File\), 93KB - ijmr_v4i2e13_app5.pdf](#)]

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Abbreviations

BMI: body mass index

BRFSS: Behavioral Risk Factor Surveillance Surveys

NHANES: National Health and Nutrition Examination Surveys

SNS: social networking site

SUPREME-DM: SURveillance, PREvention, and ManagEMENT of Diabetes Mellitus

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