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Development of a Web-based questionnaire to collect exposure and symptom data in children and adolescents with asthma

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Abstract

Background—Questionnaires are an important component of epidemiologic studies.

Maintaining compliance in longitudinal studies is a challenge, particularly from children and adolescents.

Objective—To implement a Web-based questionnaire for children and adolescents with asthma for daily self-completion, minimizing recall bias and maximizing compliance.

Methods—We determined symptoms, exposure to asthma triggers, peak expiratory flow rate, and medications taken, including dose and dose time. The Web-based system can be less time-consuming and a source of fewer errors than paper questionnaires and permits review of the data and compliance during the study. The Web programming of the questionnaire included branching, so that questions deemed irrelevant based on a previous response were not presented to participants, minimizing the completion time.

Results—Sixty-four students with asthma participated nearly daily for between 2 and 4 months. Financial incentives for the participants were calculated in real time based on completion rates. Monitoring of the subject's completion included an extensive administrative hierarchical alert system, enabling the staff to target individuals who fell behind in entries and needed the most encouragement.

Conclusions—Similar compliance and completion rates were obtained using the Web-based questionnaire as reported for smaller paper questionnaires by parents of children. The Web-based system provides a mechanism to obtain daily responses directly from an age group not often accessible by traditional questionnaire approaches.

INTRODUCTION

Questionnaires are a fundamental tool in epidemiologic studies to determine health outcomes and exposure to toxic agents. Traditional approaches for gathering responses have involved either interviewing the participant (in person or via telephone) or leaving a paper copy for the respondent to complete.¹ For longitudinal studies, the former is time-consuming for the study staff, whereas the latter relies on the diligence of the participant without feedback from the investigators until the questionnaire is submitted. Issues related to paper questionnaires include the following: (1) obtaining timely completion of daily questionnaires; (2) relying on long-term recall for completion when the participant completes the questionnaires retrospectively, which can lead to recall bias; and (3) transcription errors when transferring the written responses to an electronic database.

Compliance with questionnaires can be particularly problematic for adolescents and children. Web-based surveys have been used recently to gather information from many respondents about public health concerns,²⁻⁴ to improve recruitment for participation in a survey,⁵ to evaluate patient compliance with following medical instructions,⁶ and to answer a series of questions about asthma and fruit consumption.⁷ Web-based surveys have been as effective as paper surveys in terms of completion rate and successful ascertainment of responses to questions about potentially sensitive personal issues.^{7,8} Thus, it seems feasible to obtain information in epidemiologic studies through Web-based systems that have improved confidence compared with paper surveys and can provide rapid feedback about compliance.

We developed and used a Web-based questionnaire in a study of children and adolescents with asthma to construct a database in near real time. This database made it possible to determine if the questionnaire was being completed in a timely fashion or if days were being skipped. Our system also created electronic reminders to alert the study staff to contact a participant about missed days. Some potential advantages that we identified in our Web-based questionnaire compared with issues that sometimes are reported in a traditional paper questionnaire are listed in Table 1. The questionnaire inquired about health status, medication use, symptoms, and exposure for use in an epidemiologic study on the association between asthma responses and exposure to air pollution.

METHODS

The same considerations for developing a paper questionnaire (ie, what questions to include, compliance, pilot testing, incentives, and time for completion) and aspects specific to Web-based systems (ie, participants' access to computers; compatibility across different computers, operating systems, and Web browsers; accessing data; and real-time uses of the responses) were part of the method and study design. The study was submitted to the UMDNJ (University of Medicine & Dentistry of New Jersey) institutional review board for human subjects, and approval was received. As part of the institutional review board submission, screen images of all questions were provided with the application.

The questionnaire was designed to be as short as possible, posing only questions needed to answer the study's hypotheses, and the ordering of questions was designed to be compatible with a Web-based presentation. Thus, questions were grouped by topic, and the groups were internally linked as part of our database programming so that a smooth transition between questions and sections would be achieved when displayed on the computer screen (Fig 1).

The Web-based questionnaire was initially evaluated with a month-long pilot study of 10 students to determine if the questions were unambiguous, successfully elicited the required information, and could be completed in a sufficiently short time to make it practical to be completed daily. A parent provided his or her written informed consent for all students who were minors and, in addition, students aged 12 to 17 years provided their informed assent and those younger than 12 years assented verbally.

The Web-based questionnaire was composed of multiple sections (Table 2). Logging onto the system required a user identification number and password, which were selected by the participant. If either or both were forgotten, they could be sent electronically on request to the registered e-mail address associated with the user. The response format was designed with pick lists and check boxes to facilitate completion. Entries for the current day and the previous 3 days were permitted to allow for completion of the questionnaire after a weekend while limiting the length of recall time to attenuate potential recall bias. After completing each section, a summary of the entries was provided to the student for verification, and editing if necessary, before saving the results to the database. The student could stop and restart entries after each major section by signing off and then back onto the system. The time of day when the entry was made was saved, and the next permitted entry was prompted for when the user signed on at a later time. Each reported symptom or medication use required the participant to enter the time of day along with the duration or amount, respectively. The question about general asthma condition ("How would you rate your asthma today?") was asked before and after the individual entries about asthma symptoms as a check on the response and to determine if a different response to the same question was elicited after asking about individual symptoms.

A baseline questionnaire was administered in person by the study staff (S.H.W., A.T., S.A., and K.B.) to obtain personal information and detailed medical information, types of asthma triggers the participant typically encountered, and participant's home environment. This interview provided an opportunity for the study staff to distribute and demonstrate the use of the handheld peak expiratory flow meter for recording of peak expiratory flow measurements, demonstrate how to use the Web-based system, and observe the participant enter several days of data and answer questions about the data entry. For most subjects, this was the only in-person contact with the staff other than monthly group meetings. These meetings were designed to encourage continued regular participation, with pizza and small door prizes provided, and to distribute honoraria.

Information from the baseline questionnaire was used to customize the Web-based survey to only display those medications used by that student. The student had the ability to easily modify this pick list to change dosage or to add or delete medications from a database of more than 250 individual prescription and over-the-counter medications, including all

asthma medications. The investigators were alerted to any changes in medication use made by the participants. Data entry included the dose levels and types of administration (puffs, pills, or liquid), the actual time of day, and amount taken. An additional component of the medication procedure was to prohibit the entry of medications considered in conflict (such as 2 different brands of inhaled corticosteroids) or excess dosage greater than what would normally be prescribed by a physician, without a specific request for an override. The system was programmed to provide an alert to the investigators whenever that happened so that the participant, parent (if a minor), and/or the participant's physician could be alerted to the possible inappropriate medication use. If a medication was not already in our database, the staff was sent a special alert and it was incorporated into the medication database within 2 days.

A series of reports, alerts, and logs were programmed into the Web entry and administrative monitoring system to aid in determining compliance by the participants and to quality ensure that the entries were physically meaningful. The entries themselves were limited to physically reasonable values (eg, the peak expiratory flow rate entry had to be within the values likely for a child). An alert system notified the staff person when a particular participant had fallen behind in submitting his or her daily entry, so that we could proactively intervene to try to avoid the occurrence of missing data. The system was semiautomated: the responsible staff member had a list of potential alerts that could be sent at her discretion. There were 3 part-time staff personnel (A.T., S.A., and K.B.) monitoring the 64 participants. Three students discontinued participation after fewer than 14 days, our a priori minimum participation level for analysis, leaving 61 students for study analyses.

The Web-based questionnaire allowed for sections identified as not being relevant based on a response to a previous question to be skipped. This is in contrast to paper questionnaires, in which the subject would typically see a statement phrased as, "If you answered 'NO' skip the next section and continue at question __," requiring the subject to read extraneous material, turn the page, and find the appropriate section, all taking up his or her time and impeding compliance. The Web-based system also required a response to essential questions before the next section was displayed so that all questions were answered. Paper questionnaires allow the participant not to answer questions, resulting in missing data. This can occur intentionally or unintentionally, such as when a section is only to be answered based on an earlier response, particularly if the response necessitating the additional section occurs rarely for that subject. The Web-based questionnaire can be programmed to always present all appropriate sections.

RESULTS

During the pilot study, a number of problems in the coding, ordering of the questions and sections, phraseology of the questions, and incompatibilities of the Web program with some operating systems were identified based on direct feedback from the participants and internal checks programmed to monitor the system's function and the data produced. The results of the pilot study were used to correct the program errors and to streamline and clarify the questionnaire.

Completion time is a factor that can affect compliance. The median time required to complete the daily entries was less than 7.5 minutes, based on when individuals started and stopped each session. However, many students perform more than one task, such as instant messaging numerous friends, conducting Internet searches, composing e-mails, and doing homework assignments, at a single time (ie, multitasking), which would lead to our overestimating the time needed for completion of the questionnaire. Different individuals had different median times for completion depending on their response to questions that controlled branching within the program and their computer skills. No one complained that it took more than 10 minutes to complete each day, suggesting that using a Web-based questionnaire to obtain information was efficient for the age group participating in the study. There was a learning curve in completing the daily questionnaire, with the completion time being longer during the first few sessions and subsequently reaching a plateau for each individual. The Web-based questionnaire was completed by 61 participants over periods ranging from 27 to 141 days. The number of days each subject participated in the study varied because a rolling registration was used based on when the subject was contacted and a meeting with a staff member arranged. The ending date was the last day of the school year. The overall completion rate (days with entry of all components, consisting of symptoms and exposures, medication, and peak expiratory flow rate) for the study duration was 85.3% (4,777 of 5,601 participant-days). The completion rate varied across subjects; 32 (52%) completed 90% of the eligible days or more, 44 (72%) completed 80% of the eligible days or more, and 61 (100%) exceeded 50% of the eligible days (Fig 2A and B). Overall, today's children and adolescents who have the socioeconomic means have used computers for most of their lives and often spend significant portions of their free and "homework" time using a computer. Thus, we believe children and adolescents are an ideal group to be queried using a Web-based system.

DISCUSSION

The daily evaluation of individual compliance permitted the staff to focus their efforts on encouraging the least compliant individuals to complete the questionnaire daily, minimizing lost days of data and dropouts from the study. To minimize recall bias, the Web-based system only allowed completing dates within a 3-day period. This type of restriction is more difficult to monitor or enforce when using paper questionnaires.

The real-time evaluation of the completion rate while the study was ongoing was used to calculate individual financial incentives provided to the participants on approximately a monthly basis. The initial incentive structure was based on the number of days and full weeks of entry completed (\$1 per day and \$5 for a nearly complete month). The availability of completion rates for each question during the first few weeks of the study was used to determine that the peak expiratory flow rate was not being recorded by some subjects. Peak expiratory flow rate was considered important to collect, because it is one of the few objective measures of asthma condition that a person with asthma could supply on his or her own. The participants generally entered the data for the previous day, so they could no longer measure the peak expiratory flow rate at the time of data entry. The participants were shown several alternate methods for recording the peak expiratory flow rate until they were ready to enter it in the Web-based questionnaire, and additional financial incentives were

provided to participants who included peak expiratory flow rate entries. This approach increased the recording of the peak expiratory flow value across the participants. In contrast, it would be difficult to rapidly calculate individual participant completion rates if data were entered using the paper questionnaire method. The current Web-based system could potentially be used to track essentially any size population. Our local monthly meetings seemed to help foster retention and compliance; advertise the study during the initial months, thereby assisting our recruitment of additional subjects; and address a parental concern about their child possibly receiving a single large payment at the end of the project by enabling us to give multiple smaller payments in person.

The current system enabled the investigators to track responses to any specific question daily, facilitating the preparation of interim reports. This system also eliminated errors associated with manually transcribing data from paper copies into a computer database or the necessity of scanning in individual forms. Entry errors by the subjects were still possible, as can occur with paper questionnaires, but could be discovered and addressed earlier in the study. For example, through ongoing monitoring of results, the researchers observed that the peak expiratory flow data from one subject were being reported as a constant value. A constant peak expiratory flow rate is unlikely because of the typical small variations that exist in anyone's true peak expiratory flow value and normal uncertainty in reading the handheld meters used in the study. This alerted the study team to potentially problematic results from this individual early in the study.

The monitoring of responses also allowed for the evaluation of complaints by a subset of participants who indicated that the amount of time necessary to complete the questionnaire in solely a negative fashion (all symptom responses being "no") seemed not worthwhile, so they were considering withdrawing from the study. It was possible from evaluating the accumulated database to confirm that these participants had few, if any, reported asthma symptoms since they had begun the study. We then modified the system just for these participants, permitting them to skip sections if they remained asymptomatic but to switch back to the full questionnaire when they had any asthma-related symptoms, rather than their withdrawing from the study because of lack of interest. Peak expiratory flow rates were still requested from these subjects on all days so that this objective measure could be routinely obtained.

Previously, studies have reported moderate success using a Web-based survey and monitoring tool to track patients with asthma⁹ and that an Internet questionnaire vs a paper version was preferred by children.⁸ The limited number of children and adolescents with active asthma in the study area precluded dividing the study population to compare the compliance and completion rate for those using a paper questionnaire vs the Web-based system. A review of the literature found that few studies give detailed information on the completion rate of the instrument used or reported peak expiratory flow values. The completion rate for daily paper questionnaires of asthmatic children's symptoms and peak expiratory flow for 5 studies identified in the literature are summarized in Table 3, along with the results from this study. The response rates obtained for the current Web-based system (with data entry directly by the children) are similar to those reported in other studies that used paper questionnaires and that tended to include fewer questions and in which the

parents were sometimes responsible for completing and mailing the questionnaire responses. The Web-based system also permitted an easy entry method for obtaining detailed information on the time of day that symptoms occurred, medication taken, and where the child spent his or her time. Differences between parent and child reports of asthma symptoms in the child have been published, with parent's reports underestimating the number of symptoms compared with their children's reports.^{15,16} The Web-based system also has the advantages of immediate access to results for preliminary analyses and for calculating incentives for participants based on response rate, identifying individuals who are not completing the questionnaire routinely or within a short time so that steps may be taken during the study to try to minimize recall bias, and reducing errors involved in the transcription of data. The data collected in this study are being evaluated to determine whether associations exist between the participants' peak expiratory flow rates or symptoms of asthma and air pollutant concentrations measured in the community (sulfur dioxide and particulate matter). Overall, the Web-based system provides a mechanism to collect frequency, duration, and time of occurrence data on symptoms, medication use, and exposure to asthma triggers daily for extended periods from children and adolescents, age groups that usually have not provided this information directly.

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Figure 1.
Flowchart of logic.

Figure 2.

Completion rates (representing the proportion of days when symptom, medication, and peak expiratory flow data were all entered by the subject) for each participant, by percentage completion (A), and number of complete and incomplete questionnaire days during the study for the 61 participants, by number of days of participation (B).

Table 1**Potential Advantages of a Web-Based Questionnaire vs a Paper Version**

Paper version	Web-based version
Administration of daily questionnaires can be time and labor intensive and paper needs periodic retrieval	The Web-based system is accessed by participants at their convenience, entry is often faster, and contact with staff is minimized
Compliance, particularly for children and adolescents, is often low for daily questionnaires	Children and adolescents use computers daily, so there is a smaller intrusion in their lives
Compliance rate unknown until attempting to retrieve data	Compliance checked in real time
Paper questionnaires require subsequent entry, with associated transcription errors	Data are directly added to the database (minimal errors), checks can be made to restrict to valid entries, and data can be reviewed quickly so participants can be contacted to resolve questions about their entries
Review requires that the response on pages be looked at again	Summary table of relevant responses can be displayed for verification at entry
Calculation of completion rates for incentive calculation done can take time, so not optimal to keep participants' interest	Can be updated daily to optimize compliance
Data not usually available until late in the study	Data can be available in real time, so decisions can be made to modify interaction with subject to optimize collection and compliance
Conflicts in medication use or inappropriate medication use cannot be readily ascertained in real time	Data can be monitored on an ongoing basis for issues identified by the investigators, such as medication use or diminution in peak expiratory flow

Table 2**Questionnaire Organization and Inquiry Description^a**

Section	Question description	No. of questions
General	General health, any illnesses affecting respiratory condition, allergy problems, and visits to a medical facility	3
Proximity to triggers	Animals, environmental tobacco smoke, odors, exercised outside; each question that had a “yes” response was prompted for a time and duration of occurrence	4
Location	Outside near school, outside hometown, on bus, or in a car; each question that had a “yes” response was prompted for a time and duration of occurrence	4
Peak expiratory flow	Record up to 4 peak expiratory flow readings and time taken	1
Asthma	That day’s severity of asthma	1
Symptoms	Had asthma attack requiring care, wheezing, tightness in chest, shortness of breath, coughing, response to allergen, response to exercise, response to laughing, had asthma flare-up, rate asthma severity, had problems doing activities requiring lots of energy, some energy, little energy; question about specific asthma type response that had a “yes” response was prompted for a time and duration of occurrence	11
Medication	A list of medications that the participant indicated he or she took (prescription and over-the-counter) was individually displayed with a check box for taking that day; if marked “yes,” a pick list for time(s) and dose(s)	All medications listed by the participant

^a Reviews of each section’s answers were provided so that the participant could readily make corrections or additions before submission.

Table 3**Completion Rates Across Studies of Questionnaires or Diaries of Asthma Symptoms**

Type of subject	Study design	Type and duration of data collection	Completion rates	Source
Asthmatic children				
Aged 10–18 y (n = 64)	Daily Web-based questionnaire and peak expiratory flow	Symptoms, peak expiratory flow, medication, and asthma triggers (141 d)	Overall, complete data on 85% of the days; 100% of individuals completed >50% of the days, 72% of individuals completed >80% of the days, and 52% of individuals completed >90% of the days	Present study
Aged 4–9 y (n = 1,528)	National Cooperative Inner-city Asthma Study	Peak expiratory flow and symptom data over 4 visits for 14 d	791 of 1528 individuals for 2 wk; with 13%, 16%, and 22% returning 1, 2, and 3 of 4 diaries, respectively	Mortimer et al, ¹⁰ 2001; and Mortimer et al, ¹¹ 2002
Aged 7–15 y (n = 82)	Parents returned weekly diaries; telephone contact	Symptom reports for 6 mo	80% returned dairies with suitable data, but the completeness rate per subject was not specified	Just et al, ¹² 2002
Healthy and asthmatic children, aged 8–11 y (n = 390)	Daily symptom questions (n = 6); contact biweekly	Daily asthma symptoms for 56 d	Valid data for >70% of days and 77% of subjects (controls, 96%; and wheeze group, 55%)	Hensley et al, ¹³ 2003
Asthmatic children, aged 9–14 y (n = 64)	Daily questionnaire returned weekly	Symptoms, medication, and peak expiratory flow for 12 wk	94% returned 75% of diaries (>50% completed >90% of the questions)	Agócs et al, ¹⁴ 1997