

INTERACTIVE WEB-BASED GENETIC SCREENING QUESTIONNAIRES: COMPARISON OF ASIAN AND AMERICAN PARTICIPANTS

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Abstract— New advances in the genetic basis of disease should be translated into medical benefits for patients. To assist primary care providers when referring appropriate patients for genetic services, web-based automated screening questionnaires (“screens”) were introduced in a previous study [1]. In the present study, user experience was evaluated and compared for Asians (from eastern countries) and Americans (from USA and other western countries) who completed these screens. Responses to a post-screen user evaluation were not statistically different between East and West groups for almost all questions requiring an opinion score. For both groups, and with extremely high statistical significance, use of web-based screens at home was favored over paper-based screens or doctor-asked questions at the clinic. Therefore, web-based genetic screening can be used to deliver genetic health care via the internet to patients in both eastern and western countries throughout the world.

Keywords— Telemedicine, telegenetics, genetic screening, interactive web-based questionnaires, automated analysis.

INTRODUCTION

Research on the genetic basis of disease advances the worldwide library of medical knowledge. These new developments in clinical genetics must reach the patients whose health may benefit from such knowledge. Although primary care physicians and other health care providers act as the gateway to genetic counseling and testing, many providers have minimal training in genetics or may not be up-to-date in the field. Thus, they may not know when or where to refer a patient for needed genetic services.

To assist patients and their health care providers in assessing whether a patient would benefit from genetic services, we introduced web-based genetic screening questionnaires [1] for use by patients at home, in the health care clinic, or wherever they may have access to an internet web browser. The screens provide an interactive format easily answered by the patients. The automated screens then return a response to the patient and/or referring health care provider with a recommendation about the appropriateness of genetic counseling. No specific diagnosis or prognosis is provided. Instead, computerized analysis of the screening data returns a binary result of either “*Counseling Recommended*” or “*Counseling Not Currently Indicated*”.

In our first trial [1] of the screening questionnaires, all 50 people who participated were either satisfied or very satisfied with their experience using the interactive forms. Although the participants represented a variety of cultural and geoethnic backgrounds, all of them live in the San Francisco Bay area of northern California. Therefore, to evaluate the acceptance of web-based genetic screening by people living in other regions of the world, our second trial, which we report here, compared user experience for participants from Asia and America.

METHODS

An online clinical genetics database with automated screening tools and internet web access for patients has been built using a standard relational database, SQL programming, server-side scripting, and HTML coding at www.GeneScene.com [1], [2]. Participants were recruited in three different settings including a medical clinic, English language classes conducted for graduate students from around the world, and the web site [2] itself. The participants used computer workstations and equipment available in their classrooms, in their homes or offices, or provided by the investigators.

Trial participants chose from 4 different genetic health screens addressing the risks for breast cancer, colon cancer, diabetes, and birth defects. After participants completed a screen and received the automated result, they then completed a separate questionnaire evaluating their experience. Table I abbreviates the ‘opinion’ questions with paraphrasing along with the indices to label the questions when reported in the other tables. Each of these opinion questions was scored as follows: 1 = “agree strongly”, 2 = “agree”, 3 = “no opinion”, 4 = “disagree”, 5 = “disagree strongly”. Demographic data were also collected including age, socioeconomic level, education, and profession, etc.

The participants represented all racial and ethnic groups, all socioeconomic levels, all levels of educational achievement, and a variety of occupations. Informed consent was obtained from all participants prior to using the genetic screening questionnaires. Of the 76 individuals who elected to participate in the study, only 5 were excluded because they did not complete both a genetic health screen and a post-screen user evaluation. Statistical analysis was completed using NCSS 2000 software [3].

RESULTS

Of the 71 participants who completed both a screen and a post-screen evaluation, 26 were from Asian countries (including India, China, Japan, and Korea labeled “*East*”) and 45 were from the United States and other western countries (including Central and South America and Europe labeled “*West*”). Ages for the East group ranged from 19 to 35 years with a mean of 22.7 years. Ages for the West group were 16 to 54 with a mean of 29.1 years. In the East group, there were 8 males and 18 females, while in the West group, there were 24 and 21, respectively. Reported education and socioeconomic levels were the same for both groups corresponding to college degrees and middle class.

Table II presents means \bar{x} and \bar{y} of the opinion scores for the East x and West y groups for each of the indexed

TABLE I
SURVEY QUESTIONS WITH OPINION SCORES

Index	Question
1	web page form was easy to read
2	form took more time to complete than expected
3	difficulty seeing the form on the display monitor
4	questions seemed too personal
5	questions made me feel anxious
6	concerned about my genetic risks
7	questions were not complicated
8	want to be screened for other genetic risks
9	questions did not make me feel nervous
10	comfortable using the computer
11	prefer that my doctor ask me the questions
12	prefer to answer questions on paper at clinic
13	prefer to answer questions on web form
14	concerned about my health
15	easy for me to concentrate on questions
16	computer equipment was distracting
17	concerned personal info may not stay confidential
18	prefer web form at home before going to clinic
19	web-based screening could save me time
20	felt embarrassed using computer
21	felt embarrassed last time went to clinic
22	enjoyed using computer
23	satisfied with experience using web form

TABLE II
EAST VS WEST FOR ‘OPINION’ QUESTIONS

Index	East \bar{x}	West \bar{y}	MWW p	KS p
1	3.5	3.8	.060	.77
2	2.8	3.6	.0028	.043
3	3.4	3.8	.027	.14
4	3.1	4.0	.00012	.0022
5	3.6	3.9	.073	.42
6	2.8	3.0	.42	.90
7	2.6	2.3	.15	.59
8	2.8	2.6	.35	.79
9	2.3	2.0	.18	.90
10	2.1	1.7	.079	.84
11	2.8	3.2	.16	.41
12	3.4	3.6	.31	.99
13	2.7	2.6	.30	.68
14	2.0	2.6	.072	.20
15	2.4	2.1	.039	.87
16	3.7	4.0	.081	.51
17	2.6	3.1	.051	.025
18	2.6	2.8	.41	.95
19	2.3	2.1	.27	.52
20	4.0	4.3	.078	.13
21	3.2	3.6	.12	.45
22	2.3	2.1	.44	.63
23	2.5	2.4	.32	.82

questions from Table I. Also tabulated are the p values for the statistical significance of differences in the distributions according to the Mann-Whitney-Wilcoxon (MWW) and Kolmogorov-Smirnov (KS) tests with two-tailed analyses. No strongly significant difference was found between East and West groups except for question 4. The groups were then pooled for Table III which compares those questions (11, 12, 13, and 18) addressing user ‘preferences’. Data in the pooled groups met the requirements for a normal distribution. Results are reported as means \bar{x} representing one question, \bar{y} the other question in the comparison, and p values for a one-tailed T test.

DISCUSSION

When comparing East and West groups, the participants’ experience using the screens differed significantly only for question 4. Whereas the West group “disagreed” that the screening questions were too personal, the East group had “no opinion”. This result may reflect some cultural differences requiring greater sensitivity.

However, our study may have had a bias for the score 3 = “no opinion” due to the form default being set to this option for each question. For our next trial, the evaluation form will be redesigned to require a specific response without a default for each opinion question. Nevertheless, we do not believe that any such bias impacted the fundamental results because of the extremely high statistical significance.

TABLE III
COMPARISON OF ‘PREFERENCE’ OPINION QUESTIONS

x Index	\bar{x}	y Index	\bar{y}	T test p
11	3.04	12	3.51	.00038
11	3.04	13	2.65	.0015
11	3.04	18	2.69	.0076
12	3.51	13	2.65	.000000
12	3.51	18	2.69	.000000
13	2.65	18	2.69	.38

CONCLUSION

With extremely high statistical significance at $p < 0.0000005$ independent of country of origin, use of web-based screens at home was favored over paper-based screens or doctor-asked questions at the clinic. Therefore, web-based genetic screening can be used to deliver genetic health care via the internet to patients in both eastern and western countries throughout the world.

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