Public Perceptions of Pharmacogenetics

WHAT’S KNOWN ON THIS SUBJECT: As technical improvements of pharmacogenetics (PGx) continue to be made, little is known about the perceptions of the public, in particular parents and children, on the topic of PGx.

WHAT THIS STUDY ADDS: If PGx testing is for oneself, differences in opinion are due to baseline PGx knowledge, regardless of whether respondents are parents or not. If PGx testing is for children, parents would prioritize their own understanding above their child’s assent.

abstract

BACKGROUND AND OBJECTIVES: Pharmacogenetics (PGx) promises to optimize patient response to therapy. However, the public’s acceptance of PGx is not well known, notably when this applies to children. Our objective was to explore perceptions of PGx testing among individuals, who differ from each other by either parental status or educational exposure to PGx, and to explore parents’ views between PGx testing for oneself and PGx testing for their children.

METHODS: An exploratory survey was conducted among parents and other adults. Surveys P and C were completed by parents, survey NP by middle-aged nonparents, and survey MS by medical students.

RESULTS: Proper explanation before PGx testing appeared to be the most important issue to the respondents (eg, $P = 1.55 \times 10^{-38}$ for survey NP). Respondents who were more knowledgeable about PGx were also more comfortable with PGx testing (eg, $P = 2.53 \times 10^{-7}$ in case of mild disease). When PGx testing was for one’s child, parents valued their own understanding more than their child’s assent ($P = 1.57 \times 10^{-17}$).

CONCLUSIONS: The acceptability of PGx testing, either for oneself or for one’s child, seemed to depend on baseline PGx knowledge, but not on parenthood. Pediatrics 2014;133:e1258–e1267

AUTHORS: Steven C. Zhang, BSc, Carleton Bruce, PharmD; Michael Hayden, MD, PhD, and Michael J. Rieder, MD, PhD

“Schulich School of Medicine and Dentistry, and Departments of Pediatrics, Physiology and Pharmacology, and Medicine, and University of Western Ontario, London, Ontario, Canada; and Department of Pediatrics, University of British Columbia, Vancouver, British Columbia, Canada

KEY WORDS: pharmacogenetics, parents, child, public opinion

ABBREVIATIONS

ADRs—adverse drug reactions
CI—confidence interval
MANOVA—multiple analysis of variance
MLR—multiple linear regression
PGx—pharmacogenetics
TPMT—thiopurine methyltransferase

Mr Zhang designed the data collection instruments, carried out the initial analyses, coordinated data collection, and drafted the initial manuscript; Dr Rieder conceptualized and designed the study, reviewed the data, and revised and revised the manuscript; Dr Carleton assisted in the design of the study, reviewed the data, and reviewed and revised the manuscript; Dr Hayden reviewed the data, and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted.

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Address correspondence to Michael J. Rieder, MD, PhD, Division of Clinical Pharmacology, Department of Pediatrics, Children’s Hospital of Western Ontario, 800 Commissioner’s Rd East, London, Ontario, N6C 2V5, Canada. E-mail: mrieder@uwo.ca

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POTENTIAL CONFLICT OF INTEREST: Drs Carleton and Hayden are 2 of 5 inventors on patents and patent applications that relate to genetic polymorphisms that are predictive of hearing loss after treatment with cisplatin and genetic polymorphisms that are predictive of cardiotoxicity after exposure to anthracyclines; and Dr Rieder and Mr Zhang have indicated they have no potential conflicts of interest to disclose.
Among children, adverse drug reactions (ADRs) account for adverse events in 3% of outpatient visits and 2% to 4% of hospital admissions. By addressing genetic variability in therapeutic response, pharmacogenetics (PGx) promises to reduce the risk of ADRs. Recently, many PGx tests have become both financially affordable and clinically validated. As an example of PGx testing, when treating acute lymphoblastic leukemia, current standard of practice requires that azathioprine be dosed according to the genotype of the thiopurine methyltransferase (TPMT) enzyme. Specifically, for heterozygotes of mutant TPMT alleles (ie, alleles *2, *3A, *3B, and *4), the dosage of azathioprine should be reduced by 50% to 75%. Although for homozygotes, the dosage should be reduced by 90%.

As technology improves, PGx, on the basis of single candidate genes such as the TPMT gene, is evolving into pharmacogenomics, in which genome-wide patterns of single-nucleotide polymorphisms could be identified to help guide therapy. Thus, unlike PGx, pharmacogenomics accounts for interaction effects between multiple genes. Despite technical improvements, however, widespread clinical implementation of PGx would be difficult without public acceptance. In particular, parents' views on PGx testing should be better understood, especially since the effects of ADRs are more pronounced in children than in adults.

Plausibly, the acceptability of a concept may depend on people's familiarity with the concept. Indeed, among medical students, greater educational exposure was associated with more favorable opinions on diverse topics such as complementary alternative medicine, geriatric psychiatry, rural practice, and palliative care. In view of previous literature, therefore, the primary objective of this study was to explore how the acceptability of personal PGx testing (ie, PGx testing for oneself) could be related to parental status and educational exposure. As a primary hypothesis, we postulated that all respondents might share similar opinions regarding personal PGx testing. As a secondary hypothesis, we postulated that parents' views on personal PGx testing may differ from their views on PGx testing for their children.

METHODS
Survey Design
The current study was designed as an exploratory survey, commonly used to probe public opinion (Fig 1). To draft the questionnaire with optimal neutrality and clarity, a pilot study was first conducted. To facilitate statistical interpretation, all answer choices were presented on a 10-point Likert scale. Although most Likert scales use a 5-point or a 7-point format, the 10-point scale is also very common. In fact, the 10-point scale is easily interconvertible with both the 5-point and the 7-point scale.

To address the primary hypothesis, survey 1 was used to collect the views of medical students (representing greater educational exposure to PGx), the views of lay parents, and the views of lay nonparents (Supplemental Appendices 1 and 2). Lay parents accompanying pediatric patients were recruited from a local Pediatric Emergency Department, whereas lay nonparents were recruited from the patient pool of a local Urgent Medicine Clinic. Lay respondents were recruited from waiting rooms for either Urgent Medicine or Emergency Medicine at the local hospital, so as to approximate similar levels of illness acuity. Owing to difficulties of obtaining approval from distant medical schools, only the local medical school's student population was recruited.

To address the secondary hypothesis, parents were also invited to complete survey 2 (PGx testing for one's children), in addition to survey 1 (personal PGx testing; Supplemental Appendices 1 and 2). Following previously published methods, survey 2 is a modified version of survey 1, because facilitating decisions for someone else is similar to, but not equivalent to, making decisions for one's own benefit. To optimize the comparability of answers, pair-matched questions from survey 1 and survey 2 were written with maximal textual similarity.

The ability to read and write English was used as the inclusion criteria. Because participation was voluntary, respondents were free to give blank answers. To measure baseline PGx knowledge, research personnel refrained from specifically naming and explaining the term “pharmacogenetics.” Instead, respondents were reminded that survey questions had to be answered in the context of “DNA testing to guide therapy.” Upon further questioning, respondents would be reminded of their right to give blank answers. To ensure voluntary participation and to minimize bias, therefore, respondents’ completion of the surveys did not necessitate supervision by research personnel.

Ethics Review
Approval for this study was granted by the Research Ethics Board at the University of Western Ontario. Because surveys were anonymous and voluntary, consent for participation was verbal.

Data Analysis
χ² tests were used to quantify the proportion of invalid responses, defined in the current study as a blank answer or an answer of “don’t know.” Similarly, one-sample t tests were used to determine whether opinion...
ratings differed significantly from neutral, defined by previous literature as a rating of 5.5 on a 10-point Likert scale. Paired t tests were used to contrast responses between matched questions answered by the same respondent. Within either survey 1 or survey 2, paired questions were written to address binary variations of a similar topic. For example, within survey 2 (PGx testing for one’s children), question 4.1 (parents’ views on informed consent) was matched with question 4.2 (parents’ views on assent). Likewise, questions from survey 1 (PGx testing for oneself) were matched with questions from survey 2 (PGx testing for one’s children).

After adjusting for baseline PGx knowledge, multiple analysis of variance (MANOVA) was used to compare responses on survey 1 from the 3 respondent groups (ie, parents, non-parents, and medical students). Commonly used to identify explanatory variables for an outcome of interest, multiple linear regression (MLR) is also one of the most commonly used statistical tools in pediatric research. When MLR was used in the current study, comfort level with PGx testing for mild disease (question 2) was chosen as the outcome variable. Explanatory variables included baseline PGx knowledge (question 1), comfort level in case of severe disease (question 3), and various concerns regarding PGx testing (questions 4–12).

Originally, a total of 155 statistical comparisons were planned. In reality, fewer than 124 statistical comparisons were made (Fig 1). Nevertheless, during Bonferroni correction, the more conservative value of 155 was used. The study-wide α level was kept at 0.05, so that α level for each statistical comparison was corrected to 3.23 × 10⁻⁴ (0.05/155 = 3.23 × 10⁻⁴). The statistical software used in the current study was SPSS version 17.0 (IBM SPSS Statistics, IBM Corporation).

RESULTS

Demographics

In terms of collected copies of survey 1, 226 were from parents, 105 were from nonparents, and 236 were from medical students (Fig 1). In terms of survey 2, 229 copies were collected from parents. In total, 796 questionnaires were collected.

Proportions of Invalid Responses

According to χ² analysis, the proportion of invalid responses for
questions 2 to 12 was statistically constant across the 3 respondent groups \((P > 3.23 \times 10^{-4})\). Regardless of respondent group, the proportion of invalid responses did not exceed 10% for questions 2 to 5 and questions 8 to 12. Regardless of respondent group, the mean proportion of invalid response was 18% for both question 6 (concern with general practitioner’s inexperience in PGx) and question 7 (concern with specialists’ inexperience in PGx). However, for question 1 (used to check PGx knowledge), the proportion of invalid responses (36%) was significantly higher for lay respondents than the proportion (18%) for medical students \((P = 1.07 \times 10^{-10})\).

**Opinion Ratings for Individual Questions**

For question 1, the mean rating was significantly higher than neutral, with higher ratings indicating better baseline PGx knowledge \((P < 3.23 \times 10^{-4}; \text{Table 1})\). For questions 2 and 3 (comfort levels with PGx), the mean ratings were also all significantly higher than neutral \((P < 3.23 \times 10^{-4}; \text{Table 1})\). Likewise, for question 4 (concern with proper notification), question 5 (concern for separate consent), question 9 (concern for private cost), and question 11 (concern for health insurance discrimination), the mean ratings were significantly higher than neutral \((P < 3.23 \times 10^{-4}; \text{Table 1})\). In contrast, for questions 6 and 7 (concern for physicians’ ignorance), the mean ratings were significantly lower than neutral \((P < 3.23 \times 10^{-4}; \text{Table 1})\).

For most survey questions, the mean opinion ratings differed significantly from neutral \((P < 3.23 \times 10^{-4})\), except question 8 (concern for public cost), question 10 (concern for wait time), and question 12 (concern for employment discrimination; Table 1). For questions 2 to 12 was statistically constant across the 3 respondent groups \((P > 3.23 \times 10^{-4})\). Regardless of respondent group, the proportion of invalid responses did not exceed 10% for questions 2 to 5 and questions 8 to 12. Regardless of respondent group, the mean proportion of invalid response was 18% for both question 6 (concern with general practitioner’s inexperience in PGx) and question 7 (concern with specialists’ inexperience in PGx). However, for question 1 (used to check PGx knowledge), the proportion of invalid responses (36%) was significantly higher for lay respondents than the proportion (18%) for medical students \((P = 1.07 \times 10^{-10})\).

**Views of Different Respondents**

As shown in Fig 2, in the case of personal PGx testing, the mean level of concern for health insurance discrimination (question 11) was significantly higher for medical students than for parents \((7.87 \text{ vs } 6.55, \ P = 1.15 \times 10^{-5})\). The mean level of concern for employment discrimination (question 12) was significantly higher for medical students than for nonparents \((6.94 \text{ vs } 5.21, \ P = 3.49 \times 10^{-5})\). After adjusting for baseline PGx knowledge, mean opinion ratings were statistically equivalent across the 3 respondent groups \((P > 3.23 \times 10^{-4})\) for questions 1 to 10 (Fig 2).

In Fig 3, for both question 2 (mild disease) and question 3 (severe disease), the level of comfort with PGx was higher in the presence of baseline PGx knowledge than in its absence \((\text{question 2: } 8.30/7.34, \ P = 2.53 \times 10^{-7}; \text{question 3: } 9.27/8.60, \ P = 3.99 \times 10^{-6})\), regardless of respondent group.

For all survey questions, interaction terms between respondent group and baseline PGx knowledge were not significant according to MANOVA analysis.

**PGx Testing for Oneself Versus PGx Testing for One’s Child**

In survey 2 (PGx testing for one’s child), the mean rating for question 4 (importance of parental notification) was significantly higher than the rating for question 4.2 (importance of children’s assent; 95% confidence interval [CI]: 1.35 to 2.06, \(P = 1.57 \times 10^{-17}\); Table 2). For question 9 (private cost), there was a statistically nonsignificant tendency for levels of concern to be lower in survey 2 (parents for their children) than in survey 1 (parents for themselves; 95% CI: \(-0.24 \text{ to } -0.08, \ P = 5.26 \times 10^{-4}\); Table 2).

**Opinion Ratings for Paired Questions**

For all respondents, the average comfort level with PGx testing was significantly higher for question 3 (severe disease) than for question 2 (mild disease; \(P < 3.23 \times 10^{-4}\), Table 3). For lay respondents, mean opinion ratings for question 6 (general practitioner’s expertise in PGx) and question 7 (specialists’ expertise in PGx) were statistically equivalent \((P > 3.23 \times 10^{-4})\); Table 3). In contrast, for medical students, question 7 (specialists) received higher ratings than question 6 (GPs; 95% CI: 0.55 to 1.07, \(P = 4.26 \times 10^{-9}\); Table 3).

Unlike questions 9 and 11, individual responses for questions 8 and 12 were not distributed along a unimodal curve. Thus, it was difficult to compare the mean rating for question 8 (concern for private cost) with the mean rating for question 9 (concern for private cost). Likewise, it was difficult to compare the mean rating for question 11 (concern for insurance discrimination) with mean rating for question 12 (concern for employment discrimination).

**Predictors of Comfort With Routine PGx Testing**

For all 3 respondent categories, MLR identified that comfort level with personal PGx testing, in the case of mild disease (question 2), only had 2 significant predictive variables: the first was baseline knowledge level (question 1; \(\beta_2 = 0.784, \ P = 1.35 \times 10^{-64}\)) and the second, comfort level when disease is severe (question 3; \(\beta_2 = 0.784, \ P = 1.35 \times 10^{-64}\)). In the case of PGx testing for one’s child, the only significant predictor of comfort level with PGx testing, in the case of mild disease (question 3), was comfort level in case of severe disease (question 3; \(\beta_1 = 0.765, \ P = 1.35 \times 10^{-18}\)). In questions 4 to 12, respondents were asked to consider potential concerns for PGx testing, such as improper consent, physician ignorance, financial cost, wait time, and social discrimination. According to
TABLE 1 Determining Whether the Mean Survey Response Is Significantly Different From a Neutral Opinion Rating

<table>
<thead>
<tr>
<th>Question</th>
<th>Nonparents</th>
<th>Medical Students</th>
<th>Parents</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (n)</td>
<td>95% CI</td>
<td>P</td>
<td>Mean (n)</td>
</tr>
<tr>
<td>1</td>
<td>7.56 (58)</td>
<td>1.28 to 2.64</td>
<td>(3.14 \times 10^{-7})</td>
<td>7.32 (194)</td>
</tr>
<tr>
<td>2</td>
<td>8.50 (102)</td>
<td>2.34 to 3.30</td>
<td>(4.65 \times 10^{-19})</td>
<td>7.58 (232)</td>
</tr>
<tr>
<td>3</td>
<td>8.94 (100)</td>
<td>3.02 to 3.68</td>
<td>(2.08 \times 10^{-19})</td>
<td>8.10 (231)</td>
</tr>
<tr>
<td>4</td>
<td>9.38 (104)</td>
<td>5.50 to 2.45</td>
<td>(1.53 \times 10^{-18})</td>
<td>8.35 (233)</td>
</tr>
<tr>
<td>5</td>
<td>7.56 (58)</td>
<td>1.28 to 2.64</td>
<td>(3.14 \times 10^{-7})</td>
<td>7.32 (194)</td>
</tr>
<tr>
<td>6</td>
<td>8.39 (80)</td>
<td>2.20 to 0.82</td>
<td>(3.74 \times 10^{-5})</td>
<td>3.75 (207)</td>
</tr>
<tr>
<td>7</td>
<td>3.96 (80)</td>
<td>2.44 to 1.21</td>
<td>(8.20 \times 10^{-8})</td>
<td>2.92 (211)</td>
</tr>
<tr>
<td>8</td>
<td>5.43 (97)</td>
<td>0.73 to 0.60</td>
<td>0.041</td>
<td>5.44 (222)</td>
</tr>
<tr>
<td>9</td>
<td>8.14 (98)</td>
<td>2.12 to 3.18</td>
<td>(3.98 \times 10^{-16})</td>
<td>7.68 (228)</td>
</tr>
<tr>
<td>10</td>
<td>74.7 (99)</td>
<td>1.42 to 0.19</td>
<td>0.11</td>
<td>4.14 (224)</td>
</tr>
<tr>
<td>11</td>
<td>6.82 (60)</td>
<td>0.70 to 1.95</td>
<td>(6.10 \times 10^{-5})</td>
<td>7.82 (220)</td>
</tr>
<tr>
<td>12</td>
<td>5.21 (92)</td>
<td>1.10 to 0.43</td>
<td>0.202</td>
<td>6.34 (225)</td>
</tr>
</tbody>
</table>

For each question in each survey, the mean rating on the 10-point Likert scale is compared with a test value of 5.5. A per-comparison alpha value of 3.23 \times 10^{-6} was used. NA, not applicable.

a 95% CIs are used for the differences between mean opinion ratings and the test value of 5.5.

b Mean Likert ratings have a superscript letter only if they do not significantly differ from a neutral value of 5.5 (ie, \(P > 2.33 \times 10^{-6}\)). For these mean ratings, the distribution of individual responses followed a sharply bimodal distribution.

DISCUSSION

Personal PGx Testing

Plausibly, the acceptability of PGx testing may depend on the amount of perceived benefit from PGx-testing.29,30 In our study, it was found that all respondents had a poor understanding of PGx. The responses of questions 4 to 12 were not predictive of responses to question 2.
Dissimilar Opinions Regarding Personal PGx Testing

Compared with parents, medical students were significantly more concerned with the issue of health insurance discrimination, an ethical issue that is still under active debate.\textsuperscript{36,37} In terms of baseline PGx knowledge, although 36% of lay respondents misidentified the definition of PGx, up to 18% of medical students fared just as badly. Thus, our findings support current literature suggesting that medical education on PGx can be improved.\textsuperscript{29} Indeed, according to the International Society of

**Figure 2**

According to MANOVA analysis, the level of concern for taking PGx tests varied significantly among different respondent types (denoted by asterisk), for concerns either relating to insurance discrimination (A; $F = 21.7; P = .024$) and employment discrimination (B; $F = 1.62; P = .199$). The level of concern for taking PGx tests was statistically equivalent between those with incorrect and those with correct knowledge of PGx, for both insurance discrimination (A; $P = .183$) and employment discrimination (B; $P = .755$). The interaction term Respondent Type $\times$ Baseline PGx Knowledge was not statistically significant, for both insurance discrimination (A; $P = .945$) or employment discrimination (B; $P = .502$).

**Figure 3**

According to MANOVA analysis, the level of comfort with PGx significantly diverged between incorrect and correct baseline PGx knowledge, for both mild disease (A; $F = 27.7; P = 2.53 \times 10^{-7}$) and severe disease (B; $F = 21.7; P = 3.99 \times 10^{-6}$). At an $\alpha$ value of $P = 3.23 \times 10^{-4}$, the level of comfort with PGx was statistically constant across the 3 respondent groups, for both mild disease (A; $F = 5.74; P = .024$) and severe disease (B; $F = 0.123; P = .884$). The interaction term Respondent Type $\times$ Baseline PGx Knowledge was not statistically significant, for both mild disease (A; $F = 1.72; P = .180$) and severe disease (B; $F = 1.62; P = .199$).
Pharmacogenomics, at least 4 hours of PGx teaching may need to be offered to medical students.38 Unlike other respondents, only medical students appeared to believe that GPs and specialists have different amount of expertise regarding PGx. In reality, it is known that there is great variability in physicians’ familiarity with PGx.39 Nonetheless, regardless of physician specialty, our study revealed the public has high expectations for all physicians, in agreement with the findings of other investigators.35,40

### TABLE 2 Exploring Parents’ Views on PGx Testing for Themselves and Their Views on PGx Testing for Their Children

| Question in Survey 2 (Importance of Notifying Parents) | Question 4.2 in Survey 2 (Importance of Notifying Children) | 95% CI | $P (\alpha = 3.23 \times 10^{-14})$
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean SD</td>
<td>Mean SD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.41 1.46</td>
<td>7.71 2.76</td>
<td>1.35 to 2.06</td>
<td>$1.57 \times 10^{-17}$</td>
</tr>
<tr>
<td>Question 9 in Survey 2 (Cost for One's Children as a Concern)</td>
<td>Question 9 in Survey 1 (Cost for Oneself as a Concern)</td>
<td>(Question 4 in Survey C–Question 4.2 in Survey C)</td>
<td>6.83 3.11</td>
</tr>
</tbody>
</table>

* Comparisons with $P$ values $> .01$ are omitted from the table.

### TABLE 3 Comparing Responses for Paired Questions That Focused on Dichotomized Aspects of Various Issues

| Respondent Group | Question 2 (Comfort With PGx for Mild Disease) | Question 3 (Comfort With PGx for Severe Disease) | $\alpha = 3.23 \times 10^{-4}$ | Statistical Significance | $P$
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>95% CI (Question 2–Question 3)</td>
<td>$P$</td>
<td></td>
</tr>
<tr>
<td>Nonparents</td>
<td>8.32 (2.45)</td>
<td>8.93 (2.14)</td>
<td>$-0.86$ to $-0.35^a$</td>
<td>$6.83 \times 10^{-6}$</td>
<td></td>
</tr>
<tr>
<td>Medical students</td>
<td>7.75 (2.15)</td>
<td>9.06 (1.46)</td>
<td>$-1.56$ to $-1.07^a$</td>
<td>$7.69 \times 10^{-12}$</td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>7.85 (2.60)</td>
<td>8.90 (1.94)</td>
<td>$-1.35$ to $-0.75^a$</td>
<td>$7.89 \times 10^{-11}$</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>7.70 (2.70)</td>
<td>9.05 (1.86)</td>
<td>$1.69$ to $1.02^a$</td>
<td>$5.94 \times 10^{-14}$</td>
<td></td>
</tr>
<tr>
<td>Question 6 (Concern About GPs' PGx Skills)$^b$</td>
<td>Question 7 (Concern About Specialists' PGx Skills)</td>
<td>(Question 6–Question 7)</td>
<td>$P$</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>95% CI (Question 6–Question 7)</td>
<td>$P$</td>
<td></td>
</tr>
<tr>
<td>Nonparents</td>
<td>3.89 (3.10)</td>
<td>3.78 (2.90)</td>
<td>$0.43$ to $0.66$</td>
<td>$6.86 \times 10^{-6}$</td>
<td></td>
</tr>
<tr>
<td>Medical students</td>
<td>3.73 (2.65)</td>
<td>2.92 (2.17)</td>
<td>$0.55$ to $1.07^a$</td>
<td>$4.26 \times 10^{-9}$</td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>3.90 (2.86)</td>
<td>3.42 (2.76)</td>
<td>$0.07$ to $0.70$</td>
<td>$0.017$</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>4.07 (3.00)</td>
<td>3.45 (2.66)</td>
<td>$0.28$ to $0.95$</td>
<td>$4.53 \times 10^{-4}$</td>
<td></td>
</tr>
<tr>
<td>Question 8 (Concern About Public Cost)$^b$</td>
<td>Question 9 (Concern About Private Cost)</td>
<td>(Question 8–Question 9)</td>
<td>$P$</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>95% CI (Question 8–Question 9)</td>
<td>$P$</td>
<td></td>
</tr>
<tr>
<td>Nonparents</td>
<td>5.37 (3.32)</td>
<td>8.15 (2.70)</td>
<td>$-3.41$ to $-2.16^a$</td>
<td>$7.98 \times 10^{-14}$</td>
<td></td>
</tr>
<tr>
<td>Medical students</td>
<td>5.44 (2.99)</td>
<td>7.67 (2.29)</td>
<td>$-2.62$ to $-1.85^a$</td>
<td>$2.82 \times 10^{-24}$</td>
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<tr>
<td>Parents</td>
<td>5.67 (3.35)</td>
<td>7.47 (3.05)</td>
<td>$-2.33$ to $-1.27^a$</td>
<td>$2.64 \times 10^{-10}$</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>5.60 (3.41)</td>
<td>6.92 (3.28)</td>
<td>$-1.80$ to $-0.85^a$</td>
<td>$1.07 \times 10^{-7}$</td>
<td></td>
</tr>
<tr>
<td>Question 11 (Fear of Insurance Discrimination)</td>
<td>Question 12 (Fear of Employment Discrimination)$^b$</td>
<td>(Question 11–Question 12)</td>
<td>$P$</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>95% CI (Question 11–Question 12)</td>
<td>$P$</td>
<td></td>
</tr>
<tr>
<td>Nonparents</td>
<td>6.77 (2.98)</td>
<td>5.23 (3.50)</td>
<td>$0.91$ to $2.17^a$</td>
<td>$4.72 \times 10^{-6}$</td>
<td></td>
</tr>
<tr>
<td>Medical students</td>
<td>7.86 (2.40)</td>
<td>7.02 (2.62)</td>
<td>$0.54$ to $1.14^a$</td>
<td>$1.08 \times 10^{-7}$</td>
<td></td>
</tr>
<tr>
<td>Parents</td>
<td>6.55 (3.23)</td>
<td>5.82 (3.50)</td>
<td>$0.28$ to $0.97$</td>
<td>$4.02 \times 10^{-4}$</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>6.47 (3.23)</td>
<td>6.00 (3.40)</td>
<td>$0.21$ to $0.73$</td>
<td>$4.57 \times 10^{-4}$</td>
<td></td>
</tr>
</tbody>
</table>

$a$ The 95% CIs have a superscript letter only if they are significant at the $\alpha$ level of $3.23 \times 10^{-14}$. 
$b$ The distribution of individual responses for questions 8 and 12 follow a bimodal distribution, thereby complicating the respective comparison of their mean responses with Questions 9 and 11.
Contrasting PGx for Oneself Versus PGx for One’s Child

Previous research in pediatric oncology revealed that parents may not be distinguishing their own understanding of the situation from their child’s experiences, especially when faced with difficult treatment choices. In terms of PGx testing, it appeared that parents valued their own understanding more than their child’s understanding. Currently, how children’s assent should be properly approached is unclear, especially considering that no consensus regarding the meaning of assent has yet been reached among ethicists. The legal situation is even more complicated, especially in America, where the legal weight of assent varies greatly from state to state. Thus, as a result of different local practices in both ethics and law, the process of seeking assent for pediatric PGx testing may need to be casuistic.

Complex Opinions Difficult to Interpret

Employment discrimination, public cost, and wait time were 3 issues that appeared to polarize the opinions of lay respondents. Before 2008, the risk of discrimination as a result of personal PGx testing was raised by ethicists, either explicitly or implicitly. Since 2008, both employment and health insurance discrimination, as a result of PGx testing, have been prohibited in the United States, owing to the successful passage of the Genetic Information Nondiscriminatory Act. More recently, however, new concerns have surfaced on whether the evolving definition of genetic information, as a result of evolving technology, could hasten the obsolescence of the Genetic Information Nondiscriminatory Act.

As mentioned previously, although PGx testing is becoming more and more affordable, the respondents in our study still appeared to be uniformly concerned about private cost. In jurisdictions like Canada, public funding is available for some, but not all, medical services. In our study, the prospect of publicly funded PGx testing did not universally assure the study participants’ concerns on cost. Instead, owing to polarization of opinions on publicly funded PGx testing, how clinical PGx should be funded will likely arouse debate, at least in jurisdictions similar to Canada.

At this point, several limitations of our exploratory study deserve mention. First, although it is permissible to employ convenience sampling in an exploratory study, convenience sampling can potentially limit the generalizability of results.

Second, although the issue of assent was briefly addressed, older children capable of assent were not directly surveyed in the current study. However, it should be noted that the primary objective of the current study is to identify potential factors that influence the acceptability of PGx testing, not to focus assent, which by itself is a very complex issue, worthy of many further studies before it can be fully addressed.

Third, extra demographic data such as respondents’ age, income, and political orientation were not collected. Presumably, such data could have explained the bimodal distribution of opinions on issues such as wait time, public cost, and employment discrimination. Nevertheless, it is permissible for exploratory research to limit study variables to those that are most essential to the research objective. As well, we value the anonymous input of respondents, who might have declined survey participation when asked to provide sensitive personal data.

Despite its limitations, exploratory research is still well suited for probing public attitudes. Reassuringly, many results of the current study are in broad agreement with literature data focusing on PGx in other contexts. Thus, it is likely that new and unique findings in our study could also be reproduced. If nothing else, the findings of our study could be used as rationale for further definitive studies.

CONCLUSIONS

Our primary hypothesis was partly correct, in that a few opinions regarding personal PGx testing were shared by all respondents. In particular, for all respondents, the greatest concern with PGx testing appeared to be informed consent. As well, for all respondents, comfort level with PGx testing seemed to increase with disease acuity and baseline PGx knowledge. In the future, studies should address whether the acceptability of PGx testing to the lay public could be increased by education regarding PGx. As well, because the definition of PGx was unknown to 18% of medical students in our study, our findings are in support of recommendations calling for more PGx teaching in the medical school curriculum.

In the case of pediatric PGx testing, parents appeared to value their own understanding above their children’s. Because the concept of assent itself has different meanings in different contexts and jurisdictions, the weight of a child’s assent should be also viewed in the context of the child’s specific situation. Lastly, on issues besides assent, parents’ views on personal PGx testing for themselves, including the acceptability of testing, were not markedly different from their views on PGx testing for their children.

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