Research Article

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Pharmacogenomics

Patient experiences with pharmacogenetic testing in a primary care setting

Aim: To investigate patient experiences with pharmacogenetic (PGx) testing. **Methods:** Patients were offered PGx testing through a study on pharmacist-assisted delivery of PGx testing and invited to complete pre- and post-testing surveys about their experience. **Results:** Of 63 patients tested, 17 completed the baseline survey (27%). Interest in testing was mostly impacted by desire to inform selection of best treatment (n = 13). Seven of 12 patients that completed the follow-up survey indicated that their provider discussed the test result with them. Five patients understood their test result very or somewhat well. All would be likely to have PGx testing again. **Conclusion:** Patients perceived PGx testing to be useful, though more effort may be needed to improve patient–provider communication of test results.

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Genetic variation contributes to risk of adverse responses and treatment failure [1]. Pharmacogenetic (PGx) testing can help determine the optimal pharmaceutical therapy based on genetic risk for an adverse response or response failure for a given medication. Testing may occur at the time a treatment is needed or prospectively, in advance of treatment. Given the number of hospital admissions due to adverse drug events [2], associated healthcare costs [3,4] and the growing use of prescription drugs in USA [5], efforts to reduce the prevalence of adverse events and inform drug selection may yield both clinical and economic benefits.

Several studies have assessed public perspectives about pharmacogenetics [6,7]. Many studies suggest high patient interest in PGx testing [8–12], particularly to improve drug outcomes and predict the risk of serious adverse events, with lower interest in testing for mild adverse events [9]. In addition to the perceived benefits of PGx testing, several concerns have been raised including cost of the test and insurance coverage, the predictive value of the test, testing turnaround time, privacy, affordability of recommended drug based on the test result and patient sovereignty [7,13–17]. The limitations of PGx testing to definitively determine which side-effects patients may experience has also been perceived as a weakness of testing [9,10].

Few studies have provided insight on patient experiences with PGx testing. One study examined experiences of research participants who received PGx testing [18] and another surveyed consumers who had obtained PGx testing through a direct-to-consumer testing company [19]. Both studies reported high interest, perceived benefits of testing and limited harms. To our knowledge, no studies have explored patient interest and experiences with clinical PGx testing delivered in a primary care setting. In the current study, patients were offered PGx testing as part of a study to assess delivery models of PGx testing [20]. The

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patient survey data provide some new insight regarding attitudes and experiences with PGx testing, and areas where the clinical delivery experience can be strengthened.

Methods

Study overview

A detailed description of the study protocol is published elsewhere [20]. In summary, two primary care clinics within the Duke University Health System participated in a study to assess the impact of a provider educational intervention on the use of PGx testing between December 2012 and July 2013. All participating providers were required to attend a 1-h continuing education seminar and were provided educational materials such as a pocket guide, a poster in the physician office and brochures for patients that included recruitment information for patient surveys. Participating providers were asked to give a brochure to all patients offered testing and to notify them of their option to participate in research. After completing the baseline survey, patients were asked to provide contact information in a separate questionnaire to be recontacted for the follow-up survey. Patient participants were emailed the follow-up survey using their provided contact information; multiple emails and telephone reminders were utilized to increase participation. For each clinic, the decision to offer and conduct PGx testing was made solely by the PCP within the context of standard clinical care. The study was approved by the Duke University Health Systems Institutional review Board and registered in Clinicaltrials.gov (NCT01600846).

Pharmacogenetic testing

Single-gene (or gene pair for warfarin) PGx testing was performed by Mayo Medical Laboratories (MN, USA), a CLIA-certified laboratory. Testing was provided at no cost to the patient or the participating clinics. Test results were provided to the ordering physician. A pharmacist was available for consultation upon request regarding interpretation of test results or recommendations for drug selection or dose adjust based on the PGx test results. The physician was responsible for reviewing the test result with the patient.

Patient surveys

All patients offered PGx testing were invited to complete a baseline survey online. The baseline survey collected patient demographics, experiences and beliefs about prescription medicines and perceived risks and benefits of PGx testing. Patients that consented to testing were also invited to complete a follow-up survey, approximately 3 months after completion of the baseline survey. The post-test survey assessed receipt of test results, information-seeking behavior, medication adherence, satisfaction with test results and knowledge of adverse drug reactions. To assess respondents' beliefs about the need for and related concerns about medications, we used the validated Beliefs about Medicines Questionnaire (BMQ) at baseline and follow-up which consists of ten items across two scales: perceived necessity of medications and concerns with taking medications [21]. To measure adherence, we used the validated 8-item Morisky medication adherence scale [22] at follow-up. To assess the psychological impact of the PGx test results at follow-up, several questions were adapted from the Multidimensional Impact of Cancer Risk Assessment questionnaire [23]; answer responses were 'never', 'rarely', 'sometimes' and 'often'. Newly developed questions specific to pharmacogenetics were also included to assess patients' experience and prior knowledge and perceived value of testing. As patient identifiers were not included in surveys, clinical data including PGx test results were not linkable to survey responses. Providers were also surveyed and chart reviews conducted to gather additional clinical data; these findings will be published separately.

Analysis

Summary statistics were calculated for all questions. Likert responses for the BMQ were scored 1 (strongly disagree) to 5 (strongly agree). Analysis of individual questions and total scores for each specific scale (necessity and concerns; score range: 5–25) and general scale (overuse and harm; score range: 4–12) were tallied; a higher score indicates greater agreement (stronger beliefs). Using the scoring recommendations developed by Morisky *et al.* [24], yes/no responses to the Morisky medication adherence survey were coded as '0' and '1', respectively and summed (a total score of 8 = high adherence, 6–7 = medium adherence and <6 = low adherence). Pre- and post-test scores were analyzed using the Wilcoxon signed rank *t*-tests (alpha level: 0.05).

Results

Patient characteristics

Sixty-four patients were eligible and offered PGx testing; all but one consented to undergo testing. Patients were primarily female (68%), 50 years of age or older (84%) and white (67%). Of the seven eligible drugs for which testing was available, simvastatin was the most common drug prompting testing (71%).

A total of 17 patients completed the baseline survey (27%). Twelve of the 17 patients who completed the baseline survey completed the 3-month follow-up

survey (one did not complete the baseline, but completed the follow-up survey). For the baseline survey, ten respondents were women, 13 were 50 years of age and older, 11 had a Bachelor's degree or higher and 13 had private insurance (see Table 1). Nine patients reported their overall health status to be excellent or very good.

Experience with & knowledge of genetics & PGx testing

The majority of patients (n = 15; 88%) self-reported that they understood how genetic testing can be used in healthcare very well or somewhat well. Fifteen patients (88%) also reported that neither they nor a family member have had genetic testing to predict or diagnose

Table 1. Summary of respondent demographics.

Characteristic	All patients eligible for PGx tested (n = 63)†	Completed baseline survey (n = 17)	Completed follow-up survey (n = 12)
Female	43 (68%)	10 (59%)	5 (42%)
Age (years):			
– 18–49	10 (23%)	4 (24%)	2 (2%)
– ≥50	53 (84%)	13 (76%)	10 (83%)
Race:			
– White	42 (67%)	12 (71%)	11 (92%)
– African–American	20 (32%)	5 (29%)	1 (8%)
– Other	1 (2%)	0	0
Education:			
– High school graduate or GED	NA	4 (24%)	1 (8%)
– Some college (no degree)	NA	2 (12%)	2 (2%)
– Bachelor's degree or higher	NA	11 (65%)	9
Insurance status (patients could select multiple responses):			
– Private	32 (51%)	13 (76%)	8
– Public (Medicare or Medigap)	27 (43%)	7 (41%)	5 (42%)
– Indian Health Service	NA	1 (6%)	0
– Single service plan	NA	2 (12%)	2 (2%)
– Prefer not to answer (not recorded)	4 (6%)	1 (6%)	1 (8%)
Health status:			
– Excellent	NA	4 (24%)	4 (33%)
– Very good	NA	5 (29%)	4 (33%)
– Good	NA	7 (41%)	4 (33%)
– Fair	NA	1 (6%)	0
– Poor	NA	0	0
Drug for which PGx testing ordered:			
– Simvastatin	45 (71%)	NA	NA
– Fluoxetine	5 (8%)	NA	NA
– Clopidogrel	1 (2%)	NA	NA
– Warfarin	4 (6%)	NA	NA
– Celecoxib	2 (4%)	NA	NA
– Metoprolol	5 (8%)	NA	NA
– Codeine	1 (2%)	NA	NA

†Data obtained from chart review.
GED: General educational development, high school equivalency; NA: Data not available or not collected; PGx: Pharmacogenomic.

a disease or condition. However, four patients (24%) reported that they or a family member have had a PGx test. The top three factors that impacted patients' decisions to have PGx testing were perceived value of test to optimize treatment (n = 11; 65%), understanding that testing would help their physician select the best medicine for them (n = 13; 76%) and their physician's recommendation for testing (n = 10; 59%). When considering their decision to have testing, most patients indicated that they did not consider the potential risk of discrimination (n = 12; 71%), their family history of side effects or nonresponse (n = 12; 71%), the need to provide a DNA sample for testing (n = 11; 65%), the potential to be prescribed a more expensive medication based on test result (n = 11; 65%) or concern about having a genetic test ordered and reported by a nongenetics professional (n = 11; 65%).

Patient experiences with medications

The majority of patients (n = 14; 82%) reported taking a prescribed medication in the past year, averaging 2.4 medications per patient (range: 0–5). Nine patients reported experiencing a side effect from a prescribed medication, seven of whom indicated that the side effect was very or extremely bothersome, with one requiring medical attention. All nine patients reported that they have stopped taking a medication in the past due to side effects; six of the nine patients reported that they had stopped of their own choice and three stopped based on doctor's orders. In addition, two of the nine patients who reported experiencing a side effect indicated that they had stopped taking a medication because they felt it was not helping their condition.

Attitudes & beliefs about medications

To assess patients' views about medication, we administered the BMQ general scales (overuse and harms) and specific subscales (necessity and concerns) prior to and after testing. At baseline, 41% of respondents felt that doctors use too many medicines (Table 2). However, one or no respondents (6%) agreed with statements about potential medication harms. For the specific BMQ scales on necessity and harms, a total of 71% (n = 12) expressed concerns about the long-term effects of taking medications and 47% (n = 8) were generally worried about taking medications. However, 59% (n = 10) acknowledged the need for medications to prevent their health from worsening.

Physician–patient communication

Three months following completion of the baseline survey, we invited patients to complete an online follow-up survey about their PGx testing experience. Eleven of the 17 (65%) patients who completed the baseline survey completed the 3-month follow-up survey. Seven of the patients reported that their physician reviewed their PGx test results, either by phone (n = 2), during a follow-up appointment (n = 2) or by e-mail or postmail (n = 3; three patients indicated that their provider had not yet shared their results, and two could not recall). For the seven patients who received results from their provider, the discussion about the test results included a description of what the test result meant (e.g., poor metabolizer; n = 5), options (or changes) for current treatment based on the test results (n = 4) as well as the relevance of test result for future treatment (n = 3) and options for drug therapy based on results (n = 3). Most reported that the physician did not disclose the actual genotype/sequence result (two did report genotype). Five of those seven patients who received results felt they understood their results very well or somewhat well. Ten of 12 patients reported that no changes were made to their medication selection or dosing.

Psychological impact of PGx testing

In response to questions regarding the emotional impact of PGx testing, nine patients indicated that they never experienced feeling upset by the test result (75%) and ten never felt guilty about their result (83%). Patients were divided regarding experiencing feelings of happiness (three responded 'never'; two-'rarely'; four-'sometimes'; three-'often') or a sense of relief (four responded 'never'; two-'rarely'; one-'sometimes'; five-'often') about their test results, possibly impacted by whether they received a normal or abnormal results (surveys did not include patient identifiers so we were unable to link them with actual test results). Four patients (33%) indicated that they felt nervous or anxious about their test result; two of those four had received their results and two were unsure or could not recall receiving results (one reported a change to their prescription).

Perceived value of PGx testing

To assess whether PGx testing impacted attitudes about their medications and adherence behavior, we asked patients about their perceived value of testing and readministered the BMQ surveys (Table 2). Most patients (n = 10; 83%) reported that they felt testing was very or somewhat helpful to their provider regarding their treatment, and many (n = 7; 58%) felt more confident that the medication prescribed would be safe and improve their condition compared with past prescriptions they have had without testing.

All patients indicated they would be very or somewhat likely to have PGx testing for another medication

Table 2. Summary of responses to beliefs about medications questionnaire (baseline and follow-up).

Belief statements	Baseline – median score† (n = 17)	Baseline – agreeing or strongly agreeing (%)	Follow-up – median score (n = 12)	Baseline – agreeing or strongly agreeing (%)
My health at present depends on my medicines	2.5	35	2.5	42
My health and future will depend on my medicines	1.5	29	3	33
My life would be impossible without my medicines	2	6	1.5	8
Without my medicines, I would be very ill	2.5	18	2	1
My medicines protect me from becoming worse	2.5	59	3	67
Total necessity score, n (range of total scores)	11 (5–21)		12 (7–20)	
My medicines are a mystery to me	3	6	1.5	0
I sometimes worry about the long-term effects of my medicines	4	71	4.5	75
My medicines disrupt my life	2	18	1	17
I sometimes worry about becoming too dependent on my medicines	3.5	24	2.5	17
Having to take medicines worries me	3.5	47	2	42
Total concerns score, n (range of total scores)	16 (11–24)		11.5‡ (7–21)	
Doctors use too many medicines	2.5	41	3	42
Doctors place too much trust on medicines	2	24	2.5	25
If doctors had more time with patients, they would prescribe fewer medicines	2.5	29	2.5	33
Natural remedies are safer than medicines	2	6	2.5	0
Total general (overuse) score, n (range of total scores)	9 (4–17)		10.5 (6–17)	
Most medicines are addictive	2	6	3.5	8
Medicines do more harm than good	2	0	2	0
All medicines are poison	1.5	0	1.5	0
People who take medicines should stop their treatment for a while every now and then	2	6	2	0
Total general (harm) score, n (range of total scores)	7.5 (4–12)		9 (4–11)	

†Likert responses for the Beliefs about Medicines Questionnaire were scored 1 (strongly disagree) to 5 (strongly agree).
‡Significant change in score between baseline and follow-up (post-testing) surveys.

if indicated. If given the option to have a pre-emptive PGx panel or testing per medication, seven respondents would want a complete PGx profile panel offered preemptively, four would want individual tests ordered as needed and one had no preference.

Sharing of PGx results

Almost all (n = 11; 92%) respondents said they would share results with other prescribing doctors; one was unsure. Eight of the 12 patients would be very or somewhat likely to share their test results with a pharmacist (four were unsure). Many respondents (n = 8; 67%) had shared their test results with their spouse/partner, other family members, friends or coworker; only one patient reported sharing results with other health providers. The majority of patients (n = 9; 75%) did not look up any additional information about the medication prescribed or the test result.

Impact on medication views & adherence

Of the 11 patients that completed the BMQ at baseline and follow-up, there were no significant changes in patient attitudes regarding perceived overuse, perceived harms or perceived necessity of medications. However, median scores for the concerns subscale significantly decreased (13–11.5; $p < 0.036$) (Table 2).

The median score of the Morisky adherence assessment at follow-up was 6 (five patients had low medication adherence and four had high adherence). We

did not assess adherence at baseline since some of the prescriptions were new and data would not have been specific for the drug for which testing was ordered.

Discussion

Patient interest and understanding will be critical in moving toward greater use of PGx testing. Little research has explored patients' use and interest in PGx testing, the impact of testing on their attitudes and adherence or their overall experience with clinical PGx testing. In our pilot study of PGx testing in a primary care setting, patients' perceived value in PGx testing, had a positive experience and were willing to have testing again. Concerns about medications significantly decreased following PGx testing, although there was minimal impact on attitudes about medications.

Patients felt more confident about taking their medication following PGx testing and believed it provided their physician with more insight on dosing. Patients' increased confidence and positive attitudes toward their medication may contribute to improved medication adherence. Increased medication adherence was reported in a retrospective study of PGx-guided intervention in psychiatric patients and a study of primary care patients taking statins although the majority of patients in our study did not have any changes made to their prescription based on the results [25,26]. We were unable to observe any changes in adherence as we did not measure it at baseline due to participants receiving new prescriptions; however we observed that overall adherence was low at follow-up. Changes in attitudes or medication behaviors will be contingent upon provider communication and patient understanding of the significance of the results for treatment. Indeed, patients have specifically noted their preference to discuss PGx testing with their provider to understand both the benefits and limitations of the test results [12,14,27]. However, just slightly more than half (seven of 12) of patients reported that their provider communicated the test results and that they understood the results. Encouraging providers to share results with patients, regardless of normal or abnormal results, will be essential to improving patients' understanding of the test results, the significance regarding the prescribed medication's efficacy and likelihood of an adverse response and to avoid repeated testing. Though participating providers completed a continuing education seminar about PGx prior to participating, the purpose of the program was to provide scientific information about PGx testing and inform physicians how to identify patients appropriate for testing. Thus, more instruction or mock sessions to provide guidance on communication of test results to patients may have increased the rate of return of results. Future offerings of the continuing education unit would benefit from incorporating recommendations about effective communication and patient discussion. In addition, development of more patient-friendly lab reports may help providers' communicate the results in a manner more understandable to patients.

The sharing of PGx results with other healthcare providers will be critical to ensure consideration of the results for new medications and to avoid duplicate testing. Patients reported sharing their results with family members; and many respondents stated they would likely share results with other prescribing physicians and pharmacists. These findings are concordant with one study regarding sharing of PGx [19]. Further, based on the genetics literature, sharing test results with family members is common practice [28,29] as many patients feel it is their duty to inform family members [30,31]. Though only one patient shared results with another provider, this may be due to the short follow-up period in which patients would have been able to see other providers.

Most importantly, patients perceived overall value in the PGx test. This is consistent with general surveys about patients' potential perceived value of PGx testing [8–11,14,32]. Many patients would be willing to undergo testing again in the future, and many indicated that they'd prefer to undergo preemptive testing to avoid any delays in treatment. It has been estimated that the use of preemptive PGx testing could be helpful in preventing a significant number of adverse events given the multiple commonly used medications with known PGx interactions that patients will likely be prescribed [33,34].

There are some limitations to these findings. Patients, mostly 50 years or older, were enrolled from two Duke University Health System primary care clinics in Durham (NC, USA) and therefore, the data may not be generalizable to other practices or institutions. Specifically, integration of PGx testing may vary among practices based on the delivery model as well as available clinical support, health system features and provider knowledge and experience. For example, at the initiation of this study, both clinics were transitioning to a new electronic medical records system, which could have impacted the integration of PGx testing, evaluation of patient medication history, and timely review of test results. Another limitation is that the study data were gathered from a small number of survey respondents, which may have been due to recruitment methods that were dependent upon providers. Offering the surveys online may have also been a limitation if participants did not have inter-

net access or did not feel comfortable using a web-based survey; however, the option to complete surveys over phone was available. These factors and general provider or research participant interest in PGx may have contributed to participant bias. Further work is needed to describe patient experiences and identify areas to improve.

Conclusion

Overall, patients found PGx testing useful and generally had a positive attitude regarding their provider's utilization of testing. Our findings indicate that patients support use of PGx testing in clinical practice to guide treatment decisions and their concern about medications decreased after testing. Additional research may explore the long-term effects of PGx testing on patient adherence, results sharing and influence on future prescribing.

Financial & competing interests disclosure

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No writing assistance was utilized in the production of this manuscript.

Ethical conduct of research

The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

Executive summary

- We assessed patient experiences with pharmacogenetic (PGx) testing provided in a primary care clinic setting regarding medication-taking, knowledge and attitudes about genetics and medications and their perceived value of testing.
- Seventeen of 63 patients who were tested completed the baseline survey, interest in testing was due to the belief that testing would help their provider select the best medicine for them (n = 13), the test result would optimize treatment (n = 11) and their provider recommended testing (n = 10).
- Seven of 12 patients who completed the follow-up survey reported receiving results from their provider, including information about the phenotype (e.g., poor metabolizer), possible changes to current therapy and the relevance of the test result for future therapy. Five of those seven patients felt they understood their PGx test result very well or somewhat well.
- Patients perceived PGx testing to be useful; however, more provider effort is needed to clearly communicate test results and their significance for treatment.

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