

ORIGINAL RESEARCH & CONTRIBUTIONS

“Getting off the Bus Closer to Your Destination”: Patients’ Views about Pharmacogenetic Testing

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ABSTRACT

Context: Pharmacogenetic testing, a form of precision medicine, has the potential to optimize medication choice and dosing. Yet, relatively little is known about the views of patients—particularly those with chronic psychiatric conditions—with respect to such testing.

Objective: To explore patients’ beliefs and attitudes regarding pharmacogenetic testing, with the goal of informing policy development and implementation.

Design: Qualitative study design using semistructured focus groups with adults enrolled in Group Health Cooperative, a large health maintenance organization in the Pacific Northwest. We conducted focus groups with patients prescribed antidepressants (pilot session plus 2 focus groups, $n = 27$); patients prescribed carbamazepine (2 focus groups, $n = 17$); and healthy patients (2 focus groups, $n = 17$).

Results: Although participants understood the potential advantages of pharmacogenetic testing, many felt that the risks (discrimination, stigmatization, physician overreliance on genomic results, and denial of certain medications) may outweigh the benefits. These concerns were shared across groups but were more strongly expressed among participants with chronic mental health diagnoses.

Conclusion: Clinical implementation of pharmacogenetic testing must address patient concerns about privacy, discrimination, quality of care, and erosion of the physician-patient relationship.

INTRODUCTION

The existence of interindividual differences in medication response is well known: variability exists among patients in terms of drug efficacy, dosage requirements, and susceptibility to adverse drug reactions. Pharmacogenetics, the study of how genetic factors influence pharmacokinetics and drug clearance first envisioned by Motulsky¹ in 1957, has a growing role in providing clinically useful prescribing guidance.² The US Food and Drug Administration currently lists 139 approved drugs with pharmacogenomic information in their labeling, with categories ranging from information about clinical pharmacology to contraindications, information for

patient counseling, and dosing considerations.³ Boxed warnings, indicating the potential for serious injury or death for individuals with specific genotypes, are in place for select drugs in anesthesiology (codeine), cardiology (clopidogrel), hematology (lenalidomide), infectious disease (abacavir), oncology (arsenic trioxide, everolimus, rasburicase), and neurology (carbamazepine, valproic acid).³ The hope is that appropriate clinical use of pharmacogenetic testing will contribute to the “triple aim” of improving population health, enhancing patient care, and controlling medical costs.⁴ Pharmacogenomics, along with related advances in cancer genomic testing, has received new attention with the

launch by President Obama of a new Precision Medicine Initiative.⁵

The value of pharmacogenetic testing will depend in part on its acceptability to physicians and patients. The literature contains some data regarding physicians’ views of pharmacogenetic testing,⁶⁻¹⁰ and others have explored the views of the general public,¹¹ but less is known about patients’ perceptions.¹² The objective of this study was to explore the views of patients with and without chronic conditions regarding pharmacogenetic testing.

METHODS

Setting and Study Design

This study is part of the Electronic Medical Records and Genomics Network, a consortium funded by the National Human Genome Research Institute to develop approaches to and investigate the utility of the clinical integration of genomic information.^{13,14} Our project is a collaboration between investigators at the Group Health Research Institute and the University of Washington, with study participants at Group Health Cooperative, an integrated health care delivery system that serves more than 600,000 enrollees in Washington and Idaho.

We selected a focus group method because interactive discussions are optimal for exploring questions of acceptability, particularly for topics about which participants may feel underqualified to opine¹⁵⁻¹⁷; participants may feel more comfortable sharing potentially negative views because the group format can provide a feeling of “safety in numbers” for

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participants.¹⁸ The study was reviewed and approved by the Group Health Research Institute Human Subjects Review Committee, and written informed consent was obtained from all participants.

Sampling Strategy and Recruitment

Prospective participants were English-speaking adults age 18 years and older identified through Group Health administrative records. To learn about the perspectives of different "types" of patients, we defined 3 patient cohorts (Table 1). As a proxy for patients who were likely to have had personal experiences with trial and error in medication selection, we selected Group Health enrollees who had been (sequentially) prescribed multiple antidepressant medications.¹⁹ To elicit the views of patients for whom pharmacogenetic testing could possibly help to avoid adverse drug events, we identified

individuals who had been prescribed carbamazepine. Carbamazepine has been associated with Stevens-Johnson syndrome (toxic epidermal necrolysis) in patients with the HLA-B*1502 allelic variant of the *HLA-B* gene, which is more common in people of Southeast Asian ancestry³; for this reason, we oversampled for Asian ancestry in this group. For comparison purposes, we identified a third cohort of patients with no particular pharmaceutical concerns or chronic conditions. We mailed 4303 letters to prospective participants describing the study and inviting them to call to enroll; 61 did so, for a total response rate of 1.4%.

Data Collection

In May 2012, we held a pilot session and 2 semistructured focus groups with the antidepressant cohort and 2 focus groups with patients prescribed

carbamazepine. In July 2012, we conducted 2 focus groups with patients without chronic illnesses. The investigators used a written discussion guide in all sessions (Table 2). Each discussion was cofacilitated by 2 members of the study team (SBT and SMF, who introduced themselves as researchers from the University of Washington) and lasted 2 hours. A court transcriptionist attended each session. We provided an informal buffet dinner and paid parking, and each participant was given \$50 in cash at the end of each session.

Data Analysis

Our analytic goal was to produce a qualitative description of participants' perceptions of pharmacogenetic testing.²⁰ We used thematic analysis and a constant comparison approach to coding.²¹ Two members of the study team performed several close readings

Table 1. Focus group composition

Variable	Antidepressant cohort	Carbamazepine cohort	Healthy cohort	Total
Eligibility criteria	Prescribed ≥ 2 antidepressants in previous 2 years; new antidepressant prescription within past 3 months, n = 27, No. (%)	Currently prescribed carbamazepine; oversampled for Asian ethnicity, n = 17, No. (%)	GHC enrollees for at least 2 years; ≤ 2 current prescriptions; exclusions: mental health diagnoses, current antidepressant or carbamazepine prescription, n = 17, No. (%)	n = 61, No. (%)
Sex				
Male	10 (37)	5 (29)	7 (41)	22 (36)
Female	17 (63)	12 (71)	10 (59)	39 (64)
Age, years				
Range	22-78	21-73	21-78	21-78
Mean	54	50	50	51
Race and ethnicity				
White	23 (85)	11 (65)	15 (88)	49 (80)
Black	1 (4)	1 (6)	0	2 (3)
American Indian	1 (4)	0	0	1 (2)
Asian	1 (4)	2 (12)	0	3 (5)
Pacific Islander	0	0	0	0
Hispanic	0	0	2 (12)	2 (3)
Other	1 (4)	3 (18)	2 (12)	6 (10)
Educational attainment				
Some high school	0	0	1 (6)	1 (2)
High school or GED	2 (7)	3 (18)	0	5 (8)
Some college	6 (22)	2 (12)	0	8 (13)
Associate degree	1 (4)	2 (12)	0	3 (5)
Bachelor's degree	9 (33)	5 (29)	8 (47)	22 (36)
Master's degree	8 (30)	4 (24)	7 (41)	19 (31)
PhD	1 (4)	0	0	1 (2)
Other advanced degree	0	1 (6)	1 (6)	2 (3)

GED = general equivalency diploma; GHC = Group Health Cooperative.

of the de-identified transcripts. The lead analyst drafted a codebook of the major themes, which was revised over several meetings of the analytic team. Transcripts and codes were uploaded into Dedoose (www.dedoose.com), an online software application for qualitative analysis. The codebook went through two substantive revisions before final coding, including independent coding of four transcripts by two team members. The lead analyst performed final coding, with review by a second member of the team.

RESULTS

Participants were aware of inter-individual differences in medication response. Many shared stories about medications that did not work, caused side effects, or were “too strong” or not strong enough. Several related having felt like “guinea pigs” or, in one case, “a test-tube baby” during a process of therapeutic trial and error. A participant in one of the antidepressant groups said, “Sometimes I’ve been prescribed a medication and then find out it’s not maybe doing the job. So we go to the next medication down the list, whereas, for some people, that first one works just fine.” The idea that genetics could make a difference in

drug response was less familiar, but some participants believed that medication response could be inherited or shared within families.

Participants Believed Pharmacogenetic Testing Could Be Beneficial

Upon introduction to the topic, participants understood the potential of pharmacogenetic testing to optimize prescribing decisions, and they could imagine clear benefits from its use. As one participant put it, “I think it’s a great idea. Who wouldn’t want more information about the proper medication to take?” Another compared pharmacogenetic testing to riding a bus: “You could jump off anywhere downtown and get to a store, but you want to get off closer to the store you’re going to.” The value of the test could be even greater in high-stakes situations: a participant who reported that her child is currently awaiting a liver transplant said, “You get the liver, and you’re on medication for a long time. If there was a test that would show us which medications are going to work for him, we’d be on that so fast! Because that’s a huge life-or-death deal.”

Participants in the antidepressant and carbamazepine groups seemed particularly sensitized to the challenges patients

can face in finding the right medication and avoiding side effects; many related stories of trial-and-error in the therapeutic odyssey. One person, a participant in one of the depression groups, shared her frustration with prior medication experiences and emphasized the value of identifying the optimal drug more quickly:

Even if it takes six months [to get pharmacogenetic test results], I have had—looking back, it’s like, you know, gee, do you think that that particular drug was what took like four years out of my life? Yeah. If somebody could go in there and figure it out in four months, yeah, that would be better.

A participant in one of the carbamazepine discussions said, “The idea that a genetic test—I know there’s some controversy there—but that it could help limit, or define, [the best] medication, that’s very appealing. I mean, I have had bad *years* on the wrong thing.” Another participant in the same session commented, “If I were taking lithium, or Depakote, or some medicine with a lot of side effects, and this test could say, well, those aren’t going to help me, I would want to be taken off of those. So I think there could be a benefit to having a complete workup of the information.”

Step	Goals/subtopics	Sample questions
Warm-up and orientation	<ul style="list-style-type: none"> - Establish rapport within the group - Introduce pharmacogenetics in a relatable way 	Different people respond differently to medications. For example, codeine—a commonly prescribed pain medication—just doesn’t work for some people. And some people may have severe reactions to medications that work just fine for others. Have you ever heard of anything like this before? Have you ever heard that <i>genes</i> might play a role in such differences?
Directed pharmacogenetic testing (for specific medication or class)	<ul style="list-style-type: none"> - Informed consent - Pros and cons - Factors influencing decision making - Information desired about results 	Would you want to know if your doctor planned to order a genetic test before prescribing medication? Would you want this kind of test if you could find out the drug might not work for you? Would you want information suggesting that you may react similarly to related drugs (in addition to the one the doctor wished to prescribe for your current condition)?
Whole-genome sequencing (including pharmacogenomic indication)	<ul style="list-style-type: none"> - Informed consent - Pros and cons - Factors influencing decision making - Data security - Information desired about results 	Would you be willing to undergo sequencing before being prescribed a specific medication (eg, at your annual physical examination)? What would you want to know about the way(s) in which your additional genetic test information might be stored? Eventually such comprehensive genetic testing might include all genes in the genome, not just those most relevant to drug prescribing. This might mean that other information relevant to your current or future health status would also be generated. What are your impressions about this possibility?

Potential Negative Effects on Quality of Care and the Physician-Patient Relationship

Some participants felt that physicians might rely too heavily on genetic results and fail to give due consideration to all possible factors; others worried that physicians might not understand how to use this new information appropriately. A participant in one of the sessions with healthy patients said, “I can see this testing as a protection for doctors, kind of a cop-out. They won’t have to work quite as hard to dig and find out, ‘What shall I prescribe this person and how much?’ Because they will have this [test result]—‘Oh, okay, we’ll use that.’ So it’s kind of a protection for doctors.”

The belief that physicians might regard genetic information as more important than other data, possibly to the patient’s detriment, was a strong motif. Of greatest concern to participants across all sessions was the possibility that physicians might rely exclusively on pharmacogenetic test results and disregard patients’ reports about how a medication is working (or failing to work). A number of patients in the antidepressant and carbamazepine cohorts related incidents in which they felt that their reports of medication problems had not been taken seriously or were actually contradicted. The following exchange, which took place in one of the antidepressant groups, illustrates several participants’ views:

PARTICIPANT 4: *I want to say that again, what really bothers me the most: you have something static, which is your genome, and the way medication reacts is all different. And all other kinds of physical situations that may affect that medication. And because [the genome is] static, would the doctor be more inclined to say ... ‘I’m sorry, that’s what the test says’?*

PARTICIPANT 1: *And look at you very authoritatively and say, “This must be in your mind. For all the other patients, it works fantastically.”*

PARTICIPANT 6: *It’s not the only piece of information. If you have had [gastrointestinal] surgery, for example, and you can’t absorb a medication, that’s not something that’s going to show up on your genetic profile.*

PARTICIPANT 7: *If you have multiple illnesses, and you take multiple medications, that’s not going to necessarily show up there either.*

Participants voiced concern about the potential for genetic information to curtail interaction and reduce trust between physicians and patients. In addition to wanting physicians to listen to their concerns and take them into consideration in decision making, participants sought assurance that, in delivering genetic results, the physician would assess the patient’s need for support:

Doctors have all this [genetic] information, and you have to look at a person’s mental state. Can they handle certain information, or does that send them off to suicide? Or what’s it going to do? I was told one time I was getting tested for cancer, and then the doctor walked out of the room. I’m like, “What? What? Who?” I’m sitting there all by myself. “You’re testing for cancer?!” So how can you deal with this information? How is that going to be handled?

In contrast, a single participant in the antidepressant group envisioned pharmacogenetic testing as an important step toward what he considered the ideal: “the doctor robot,” which would make all clinical decisions on the basis of objective data.

Some participants viewed the use of pharmacogenetic information to deny a particular “good” medication as a form of unfair discrimination, as in this example: “The only thing I don’t like about [pharmacogenetic testing is], because of certain percentages, you might not be good on a certain drug, maybe, and they make this whole list of all these good drugs you can’t have. So they would refuse certain medicines to you, your whole life.” Another participant stated that if there were only one medication available to treat a particular, serious condition, and a pharmacogenetic test indicated that the medication could cause harm, it should be up to the

patient—not the physician—to decide whether to take the risk.

Concerns about Access to Genetic Information

Notwithstanding their belief in the value of pharmacogenetic testing, participants identified potential drawbacks to its implementation in the clinic. Concerns about the potential for genetic information to be accessed and (mis)used by unauthorized persons were expressed in all groups. Breach of confidentiality; discrimination in eligibility and coverage for health insurance, long-term care insurance, and disability insurance; employment discrimination; being targeted for pharmaceutical marketing campaigns; and possible misuse by law enforcement agencies were of concern to participants.

Discrimination risks were more readily and more strongly expressed in the antidepressant and carbamazepine groups, together with concerns about social stigma associated with mental health diagnoses, as in this example from the carbamazepine group:

I already have concerns just about electronic keeping of my records, compared to the way it used to be [when] it was on all on paper. I have already experienced the lack of privacy with my primary doctor ... I have mental health issues, so sometimes without even asking—they are supposed to be kept separate—my regular doctor, ... just access[es] the mental health thing, and start[s] reading this. And they have already abused it ... That’s why I have a lot of privacy issues, because I have seen how it’s easily taken advantage of.

Participants were uncomfortable with the potential for genetic information to be shared legally beyond the health care system, such as with law enforcement agencies or in legal proceedings (eg, for disability determinations). A participant in the antidepressant cohort said:

I wouldn’t mind it so much as part of my medical record, if my medical record didn’t go to other people. Like applying for disability insurance, they go through medical records, and what they decide and they define it and interpret it in their own way. So I would be concerned about if they got ahold of genetic

Of greatest concern to participants across all sessions was the possibility that physicians might rely exclusively on pharmacogenetic test results and disregard patients’ reports about how a medication is working (or failing to work).

information and what they would do to you this time.

Participants across all three cohorts also expressed concern about access to pharmacogenetic information *within* the health care system. Participants suggested that genetic information should be restricted to clinicians with a clear need to know, and that access should be limited to data relevant to a current clinical concern, as in this comment: “If I could have it on a microchip somewhere and say, okay, ‘If I’m unconscious, you know, I give medical permission to read this.’ Yeah, I probably would go for that. But at the same time, I might say, ‘Well, I don’t necessarily want it in the chart where the person who’s making my appointment can look at it.’” Several other participants suggested that genetic information be given directly to the patient, who would be responsible for determining when it should be shared. One participant commented, “It’s us having power over the information. We still want to be a very important part of the equation. And that we get to make some decisions about how it’s used.”

Patients’ Understanding of “Genetic Testing” Is Discordant with Clinicians’ Definition

As designed, the focus group guide progressed from discussion of a narrow, single-indication pharmacogenetic test—looking at a small portion of the genome specific to a particular medication—to discussion of whole-genome sequencing, which would include pharmacogenetic results. In each of the sessions, however, we had substantial difficulty focusing participants’ conversation on the less comprehensive test scenario. In other words, participants considered “genetic testing” to refer to examination of the entire genome, and most understood the purpose of genetic testing to be predicting one’s susceptibility to heritable illness. For example, one participant in the healthy cohort said, “I came in with the idea that this is a testing of your genes, your genetic makeup, to find out if you are more predestined for a certain disease Life-threatening things, that’s what

I thought it was all about.” Overall, participants evinced little understanding of the distinction between single-gene tests, panels, and whole-genome sequencing. Participants felt that payers (and to a lesser extent, physicians) would prefer more comprehensive testing approaches for reasons of efficiency and cost-effectiveness.

Whole-Genome Sequencing Was Viewed Differently from Narrower Tests

Once we had explained the differences among single-indication testing, pharmacogenomic panels, and whole-genome sequencing, many participants told us that they regarded whole-genome sequencing as a riskier undertaking than a more narrowly focused test, even if pharmacogenetic information were the primary goal of sequencing. With the generation of additional information, participants believed, the potential for misuse and discrimination would increase as well. One participant stated:

I kind of want to know how much information they can get from that blood sample. And will they then be able to go back and use other pieces of that test in an unrelated way that [doesn’t] have anything to do with the specific treatment I need at that moment? And I also want to know, after it’s been utilized for something specific, if it can be taken out of my medical record, or once it’s there, is it there forever? If I’m using it for something very, very specific, that sort of works, but they are also getting information about my IQ, my willingness to work Monday through Friday, or my need to call in for a vacation day every three weeks, or three days? I don’t want that in there.

Several participants pointed to the 1997 science-fiction film *GATTACA*,²² in which the government constrains individuals’ life choices on the basis of their genomes, as a depiction of what could go wrong if laws and social standards fail to provide appropriate privacy protections.

Some participants said that comprehensive sequencing would also be more likely to generate information they might not want, particularly for serious health risks they “couldn’t do anything about.” The potential risks

to other family members, given that genetic information about one person says something about their first-degree relatives, were also of concern.

On the other hand, whole-genome sequencing was very attractive to a few participants who reported many seemingly unrelated health problems in themselves and in their families. One such participant said:

For me, I would find it beneficial, because I suffer from a lot of different ailments. I would definitely be like, “Yeah, give me that test,” because it could show that they are treating symptoms of a different ailment. So it doesn’t add up unless you come in with a sheet this long [gestures], by the way, all of this happens. So I think a test like that could rule out what you are treating and actually show what you have I would find this would be something very important to have in my records for my family to see, simply because of my family history. My daughter is autistic. And then on my mom’s side, we have tremors, don’t know what causes those. So it’s definitely something I’m very interested in.

These individuals expressed great interest in comprehensive testing, which they thought could provide a coherent explanation for the multitude of challenges they face.

DISCUSSION

Prior studies on patient views of pharmacogenetic testing have focused on the general public and have generally presented hypothetical scenarios with limited personal relevance to participants.^{23,24} Others have explored the perceptions and values of patients undergoing treatment of life-threatening conditions, who generally express strong support for treatment-focused genetic testing and markedly less concern about the potential risks of discrimination and breach of privacy.²⁵⁻²⁷

This study adds to the perspectives of individuals diagnosed with chronic mental-health conditions. In speaking with participants in the carbamazepine cohort, we learned that many had been prescribed carbamazepine for bipolar disorder rather than seizure disorders (a common indication for this

medication). Our study thus included a majority of individuals with mental health diagnoses. Concerns about privacy, discrimination, and unauthorized access to genetic information are a theme throughout the existing literature.^{28,29} In this study, participants in the antidepressant and carbamazepine groups voiced especially strong concerns about the potential for stigmatization, discrimination, and mistreatment resulting from pharmacogenetic testing and unauthorized access to results. Although these findings may not generalize across entire populations, they highlight an underrepresented perspective that is of particular relevance to ongoing pharmacogenetic research in neuropsychiatry.^{2,30,31} Our passive recruitment strategy may have generated a greater than usual selection bias.

Pharmacogenetics has often been described as among the most straightforward and near-term applications of genetic information in personalized medicine.^{5,31-34} An important finding of this study is that some patients who could potentially benefit from pharmacogenetic testing have substantial, deeply held concerns about the tradeoffs involved in allowing genetic information to be generated about them and maintained outside their control. Our participants were not naïve patients; they were very interested in reducing the time to optimal treatment, and many told us they had personally experienced negative effects from current pharmaceutical therapies. Even so, they did not consider pharmacogenetic testing of clear benefit. Our findings are consistent with the results of an Australian study in which chronically ill patients endorsed the potential value of pharmacogenetic testing but emphasized the need for antidiscrimination measures and a holistic approach to diagnosis and prescribing.³⁵ Avoiding a life-threatening drug reaction is obviously a good thing, but when the benefits are less compelling, patients with chronic illnesses—and perhaps especially those with potentially stigmatizing diagnoses—may decide that the risks of pharmacogenetic testing outweigh the benefits.

We were struck by the strength and prevalence of participants’ worries that physicians might overvalue genetic results to the exclusion of patient reports and the detriment of the therapeutic alliance. Although patients understood that such information could be useful in achieving optimal treatment outcomes, they nonetheless expressed misgivings about the possibility that physicians would privilege genetic results over patients’ lived experience. This message represents an important counterpoint to the enthusiastic discourse surrounding next-generation sequencing and personalized medicine. If personalized medicine is to be fully embraced by patients, it will be important to ensure that physicians’ enactment of “personalization” includes responding to the patient as an individual and not merely a collection of genomic data.³⁶

Despite the proposed central role of genetics in the coming era of data-driven health care, some patients see pharmacogenetic testing as a potential threat to communication, health care quality, and the physician-patient relationship. Participants in this study wanted pharmacogenetic testing and whole-genome sequencing to complement, not replace, other information about medication response.

CONCLUSIONS

The success of precision medicine, or the provision of “the right drug at the right dose to the right patient,” will rely on the broad acceptability of genomic testing by diverse patient cohorts.⁵ Our findings suggest that pharmacogenetic solutions designed around the needs and preferences of patients who are basically well may fail to meet the needs of patients with mental health diagnoses or other chronic conditions that may carry social stigma. Health systems and physician practices considering implementation of pharmacogenetic testing must address patient concerns about privacy, discrimination, overreliance on genomic results, and erosion of the physician-patient relationship through public outreach, physician education, and accountable oversight procedures and governance. ❖

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Life-Histories

We would wish that ... *life-histories* were found in every family, showing the health and diseases of its different members. We might thus in time find evidences of pathological connections and morbid liabilities not now suspected.

— Sir William Withey Gull, MD, 1st Baronet of Brook Street, 1816-1890, English physician, Fullerian Professor of Physiology, and President of the Clinical Society