A matter of trust: patient barriers to primary medication adherence

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Abstract

Primary medication adherence occurs when a patient properly fills the first prescription for a new medication. Primary adherence only occurs about three-quarters of the time for antihypertensive medications. We assessed patients’ barriers to primary adherence and attributes of patient–provider discussions that might improve primary adherence for antihypertensives. In total, 26 patients with incomplete primary adherence for an antihypertensive, identified using their retail pharmacy claims, participated in four focus groups. Following a moderators’ guide developed a priori, moderators led patients in a discussion of patients’ attitudes and experiences with hypertension and receiving an antihypertensive medication, barriers to primary adherence, and their preferences for shared decision making and communication with providers. Three authors analysed and organized data into salient themes, including patients’ anger about and suspicion of their hypertension diagnosis, the need for medication and providers’ credibility. A trusting patient–provider relationship, shared decision-making support, full disclosure of side effects and cost sensitivity were attributes that might enhance primary adherence. Developing decision support interventions that strengthen the patient–provider relationship by enhancing provider credibility and patient trust prior to prescribing may provide more effective approaches for improving primary adherence.

Introduction

Despite the availability of effective medications to treat hypertension [1], patients’ adherence to antihypertensive medications remains suboptimal [2, 3]. Only approximately three-quarters of patients fill even the ‘initial’ prescription for an antihypertensive medication [4–6], a phenomenon known as incomplete primary medication adherence (PMA) [7]. Drug costs can impede both PMA and sustained adherence, but even eliminating costs only modestly improves adherence rates [2, 8]. Other factors may affect PMA, such as patients’ beliefs about the need for drug therapy, mistrust of their providers and fears about side effects [2, 8–10]. Unfortunately, patients and providers are unlikely to talk about these issues at the point of prescribing [10, 11].

The majority of studies regarding PMA is quantitative and focuses on counting unfilled prescriptions and/or predicting whether variables recorded in medical claims data are correlated with PMA [4–6, 12]. To fully understand patients’ reasons for PMA, we need to recognize that filling and taking medications is a complex behavior that involves the interaction of personal and environmental factors that motivate or discourage PMA behaviors, and...
that these behaviors may be separate from those required for sustained medication adherence [9, 13]. Developing effective interventions to address PMA requires a deeper understanding of these factors, namely why patients do not fill new medications, how patients personally experience barriers to PMA and what health outcomes the patients themselves seek and prioritize. Further, because the patient ultimately decides whether to fill a prescription, efforts to improve PMA must involve the patient in the prescribing decision from the beginning and consider him an equal partner. The shared medical decision-making approach, implemented in tandem with decision support tools, facilitates collaboration between patient and physician in the treatment decision process and provides patients with the knowledge and confidence necessary to fully engage in the decision-making process [14–17]. The Patient Protection and Affordable Care Act [15] and many advocacy organizations [18–22], including Patient-Centered Outcomes Research Institute (PCORI) [23, 24], have recognized the importance and benefit of shared decision making with decision support tools and endorse their use to provide ethical and patient-centered care.

Given the low rates of PMA to antihypertensive medications [5] and the promise that shared decision making and decision support tools hold for PMA, we held focus groups with patients who did not pick up a first prescription for a new antihypertensive medication to assess barriers to PMA, attributes of the patient–provider discussion that would make PMA more likely, and patients’ preferred approaches to improving PMA through patient-oriented materials.

Methods

Patient recruitment

Eligible patients included those age ≥25 who did not pick up a filled prescription for an antihypertensive medication (see Appendix 1) within 30 days after the fill date at a single large retail pharmacy chain. From this population, we selected patients for whom the prescription was the first fill of the medication, defined as having no prescriptions for the same drug (generic or brand) within 6 months before the fill date.

In three Northeastern states in the United States (Massachusetts, New Hampshire, Rhode Island), patients who met the eligibility criteria above received a letter in late Fall 2012, signed by the vice president of pharmacy for the pharmacy chain. The letter stated that pharmacists had noticed a prescription that had been filled but not picked up, that people did not pick up prescriptions for many reasons and that the research team was conducting a series of focus groups to learn more about these reasons. Patients who wanted to participate in a focus group were invited to ‘opt in’ by contacting the lead investigator (J.M.P.). Respondents were screened by a research assistant (C.A.-C.) to confirm that each had hypertension and could identify one or more reasons why they did not pick up the prescription. Patients who reported forgetting to pick up the prescription, a duplicate prescription or travel that prevented them from picking up the prescription were excluded. Patients were added to a focus group slot on a first-come, first-served basis. The study was reviewed and approved by the Institutional Review Board of the primary author’s institution, Brigham and Women’s Hospital.

Focus groups

Focus groups were held in Fall–Winter 2012 with patients from Massachusetts and Rhode Island; no patients from New Hampshire participated. We used patients’ addresses to determine whether their residences were urban or rural; urban residences were defined as towns with population densities >1000 people/mi². At the beginning of each focus group, all participants were asked to complete a demographic survey of their race, gender, age, education and prescription drug insurance status. As a simple measure of social and family support, which has been linked to medication adherence[25], we assessed whether a patient was living alone or with others and whether the others were relatives or not. Patients also received a fact sheet explaining
the focus group research study and were given the opportunity to ask questions before providing oral informed consent. For each of the four focus group, moderators (J.M.P., P.W.) used a pre-written guide, described below, to lead the discussion. Each 2-hour focus group was audio taped and transcribed, and moderators took additional notes. Patients received $65 for their participation.

**Focus group moderator guide**

We created a focus group moderator guide after an extensive review of the medication adherence literature, with contributions from local primary care clinicians and a seven-member study advisory board that included representatives from consumer advocacy organizations, retail pharmacy associations and primary care providers. In the first section of the guide, questions addressed attitudes about and experiences with receiving a diagnosis of hypertension and a prescription for an antihypertensive medication. The second section focused on barriers to PMA, including cost, side effects, transportation/access difficulties, social support, religious/cultural beliefs and preferences for complementary medicines or lifestyle modifications. Finally, the third section covered preferences for shared decision making, including the nature of communication with providers and factors that might have changed a decision to not pick up a prescription.

**Data analysis**

Patients’ demographic data were summarized using descriptive statistics. Three of the authors (J.M.P., P.W., C.A.-C.) marked and provisionally labeled transcribed recordings and notes into key themes using standard qualitative methodologies [26, 27]. The study team then met to discuss and modify these labels, which became the basis for a coding scheme where each key theme was defined and illustrated with relevant quotations. Using the agreed upon coding scheme, the same three authors (J.M.P., P.W., C.A.-C.) independently coded notes and transcripts. Coded results were analysed using NVivo (V10.0, QSR International). The overall goal was to ensure an accurate representation of all focus group content by providing the lived experiences of the patients in their own words.

**Results**

Of 129 patients who contacted the research team, 79 (61%) agreed to be screened for the study. Of the 79, 26 (33%) patients were eligible and agreed to participate in a focus group (Table I). A total of 7 patients participated in the first focus group, 5 in the second, 4 in the third and 10 in the fourth. Most patients were insured and living with at least one family member or relative. Education levels ranged from 5 (19%) with less than a high school education to 6 (23%) with masters’ degrees or higher.

**Focus group context**

Throughout the focus groups, patients expressed anger, frustration and mistrust of their providers and the healthcare system. Many reported negative provider experiences, including one who reported, ‘You go in their office and they’re looking at a laptop. How’s the doctor know who you are by looking at a laptop?’ and ‘maybe in their little handbook [it says] “let’s not tell the person this because this will scare them out of it” or something such as that. But as you say, you’ve got to protect yourself. You’ve got to keep banging away and asking questions and not be afraid to maybe insult them a little bit as far as their expertise’. These sentiments formed the backdrop of patients’ responses to all focus group questions.

**Receiving a hypertension diagnosis and an antihypertensive prescription**

Many patients were angry about and suspicious of their hypertension diagnosis. Some felt they were wrongly diagnosed; for example, one noted, ‘There are a lot of false positives’. This and similar sentiments suggested that patients did not accept the diagnosis. Although all noted that hypertension was clinically important due to the increased risk of stroke and heart attack associated with the diagnosis, even referring to hypertension as ‘the silent killer’,
patients were often angry about and did not accept the need to take medications: ‘I didn’t like it at all. I hadn’t taken any medicine and I mean I don’t like taking medicine... I was incensed to be honest with you’. Although anger was common, most patients indicated that receiving a prescription for an antihypertensive was not a surprise, citing family history or changes in their own health. One patient commented, ‘When I found out that I had to take high blood pressure medicine I was surprised but I wasn’t, because I had gained some weight and it’s [hypertension is] hereditary in my family’. Patients were simultaneously suspicious of the provider’s motivation to prescribe: ‘it’s just script, script, script, you’re done’ and ‘Cause the drug companies and the doctors are out there, working for the dollar, in a lot of cases’. Patients wondered what might happen if they stopped taking the medication: would their high blood pressure be resolved? ‘I’ve been taking that for 2 years’, said one patient, ‘If I stop, is [my blood pressure] going to shoot right back up to 190? Or is that going to be leveled off?’

**Barriers to PMA**

Against the backdrop of anger and mistrust, patients noted cost as an important barrier to PMA: ‘You have to choose between whether [you are] putting food on the table for your children or getting your medication’. Despite this, most patients held negative opinions of more affordable generic medications, believing they were less effective. As one patient said, ‘You can tell the difference in quality’. Fears about medication side effects were nearly as common. ‘You see these commercials that they say “take this and you may experience near death and all of these suicidal tendencies”—I don’t want to be taking something [like that]’, asserted one patient, with others nodding their heads in agreement. Some patients expressed concern that taking an antihypertensive could cause another health problem that the provider might fail to disclose.

Patients’ PMA was affected by their use of other medications. If the new antihypertensive was the first antihypertensive ever prescribed, patients described pill burden related to their other chronic medications as a rationale for not using the new drug. One patient commented, ‘I was like, oh, another one? Another pill? I mean I take so many pills it’s to the point where I don’t even want to take them anymore’. If the prescription was for an additional antihypertensive in patients already prescribed one or more, comments included concern that the provider made a mistake by prescribing more than one antihypertensive, that all antihypertensives worked the same so more than one was unnecessary or that more than one antihypertensive would work too well and they would have side effects (‘I have two already and I felt that this one here, it’s going to be a third and they[’re] all supposed to work the same’). Other patients were convinced that the provider was getting a kickback from prescribing more medications. One patient said, ‘I wish they could just battle [this] blood pressure thing down to one [medication]’ to which another responded, ‘They probably can, it’s just the money thing. They want to make money. Like and they want to take from people that don’t have it’.

Patients adopted a variety of strategies in place of taking an antihypertensive. Some made lifestyle

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**Table I. Characteristics of 26 patients participating in four focus groups**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%) or mean ± SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>57 ± 12</td>
</tr>
<tr>
<td>Female</td>
<td>13 (50)</td>
</tr>
<tr>
<td>Urban residence</td>
<td>23 (88)</td>
</tr>
<tr>
<td>Race/ethnicitya</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>17 (65)</td>
</tr>
<tr>
<td>Black</td>
<td>7 (27)</td>
</tr>
<tr>
<td>Native American</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Cape Verdian</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>9 (35)</td>
</tr>
<tr>
<td>Living with ≥1 non-family members</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Living with ≥1 family members</td>
<td>15 (58)</td>
</tr>
<tr>
<td>Highest level of education</td>
<td></td>
</tr>
<tr>
<td>&lt;12 years</td>
<td>5 (19)</td>
</tr>
<tr>
<td>High school graduate or General</td>
<td>4 (15)</td>
</tr>
<tr>
<td>Development (GED) certificate</td>
<td></td>
</tr>
<tr>
<td>Associate’s degree</td>
<td>5 (19)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>6 (23)</td>
</tr>
<tr>
<td>Master’s degree or higher</td>
<td>6 (23)</td>
</tr>
</tbody>
</table>

*aPatients who indicated >1 race/ethnicity were included in multiple categories.*
modifications, for example, saying, ‘So I went back to exercising. They always say that when you exercise it’s better for you, it’s better for your pressure’. Some opted for complementary medicines like red-yeast rice, even though this product is intended to lower cholesterol. These alternatives were considered to have fewer side effects than prescription medications. As one participant said, ‘Well, the reason I didn’t want to pick up a prescription is because of what the side effects are to the drugs. A lot of prescription drugs are poison, actually. And they hurt a lot of the parts of your body. And there are natural ways to go about it’.

Preferences for shared decision making
Patients discussed four attributes of the patient–provider conversation that might promote PMA to antihypertensive medications. Trust and respect were paramount. From the provider, patients expected an honest portrayal of the diagnosis and their treatment options: ‘I prefer a factual presentation. Okay. I think it shows respect for the patient, that they have the intelligence and capability of formulating good decisions’. Patients were adamant that they wanted a full disclosure of side effects. One patient summarized, ‘The only thing [the provider] can do is tell you take [your] medicine and be honest with you about how you [are] going to feel later’. Patients equally wanted to hear about complementary medicines or lifestyle modifications that could be used in place of an antihypertensive. Finally, patients wanted information about costs so that they would know whether they could afford the medication and were not embarrassed when they could not: ‘I feel so embarrassed, but I just didn’t have the copay to pay them. So I talked to my doctor about this. I said you can’t be surprising me with these kind of things’.

Patients’ preferred approaches to improving PMA through patient-oriented materials
Patients’ preferred approaches for improving PMA through patient-oriented materials such as decision support tools coincided with their preferences for shared decision making. One patient summed up fellow participants’ thoughts: ‘I think if I was starting right today to have [a] blood pressure problem, I would, you know, want to know what all the options were. And then why did you choose this one? Why do you think this will work better for me at this time?’ Many wanted sample questions they could use to start conversations with their providers. All wanted extensive information about side effects. Although patients agreed on content, they differed as to how that content should be presented. Some preferred personal vignettes that explained other patients’ rationale for and decisions about PMA. Some wanted a frequently asked questions list that described the benefits and risks of various antihypertensive medications. Still others wanted to track their blood pressure over time.

Discussion
We held four focus groups with 26 patients who failed to pick up a first prescription for a new antihypertensive medication. Among these patients with incomplete PMA, distrust and anger regarding the hypertension diagnosis and the need for antihypertensive medications were common. Suspicions about providers’ motivations were also prevalent. Other PMA barriers included cost, misperceptions about generic medications, fear of side effects and beliefs that not more than one antihypertensive medication was needed. Patients longed to be included more actively in discussions with their providers about the initiation of hypertension treatments and suggested approaches to shared decision making and patient-oriented materials that would make PMA more likely.

Patient–doctor communication is a prime determinant of adherence [28], and physicians’ communication style can strongly influence patients’ involvement in and outcomes of the treatment process [29–31]. A recent meta-analysis estimated that patients whose providers communicate ‘well’ have 19% higher adherence and that training physicians in communication skills can improve adherence by 12% [31]. Our qualitative results are consistent with
these results, because they show that missed opportunities for collaborative discussions lead to incomplete PMA for antihypertensive medications. Patients were angry at being ‘left out’ of the treatment decision process and expressed a desire for more connected discussions with providers, including a complete disclosure of treatment options and side effects. Efforts to improve PMA should therefore involve patients in the initial prescribing decisions, offering patients opportunities to communicate their preferences [11, 32, 33].

Unfortunately, training providers to enhance communication can be lengthy and resource intensive, and it is not widely available [34]. How else can a collaborative relationship be introduced and strengthened, even as most providers (and patients) do not receive communication skills training? A promising approach is the use of decision support tools, which provide structure to the decision-making process, breaking it down into smaller, manageable steps [14] and require no formal training to use. Patients in our study endorsed the use of decision support tools, suggesting content such as sample dialog and a frequently asked questions list to get the much-needed information. With such content, decision support tools can help clarify the problem at hand and determine what treatment options best align with patients’ preferences for outcomes [35]. A 2011 Cochrane review of 86 decision aid trials found that patients’ use of decision aids led to (i) improved knowledge of options; (ii) more accurate expectations of benefits and harms; (iii) choices more consistent with informed values; and (iv) greater participation in and improvement of decision making[36]. Although patients in our study disagreed on how content should be presented, a flexible decision support tool might include multiple formats to communicate information. Together, patients and providers can then choose the optimal format or focus on the content that is most relevant to them. Other approaches that enhance communication and foster collaborative care may also hold promise; future research should focus on identifying and testing such approaches in real-world clinical settings [37] and evaluate the extent to which decision support might be integrated [38].

To our knowledge, our study is the first to examine the knowledge, attitudes and beliefs among patients, who were identified as primary non-adherent via their retail pharmacy claims. This novel method focused our work on patients who, by not filling a prescription, had decided not to engage with the healthcare system at a specific point in time. Similar to studies in which patients did fill at least one prescription, patients in our study acknowledged barriers such as cost and side effects as impediments to antihypertensive PMA, but these barriers were secondary to and described through the lens of imperfect, antagonistic and/or mistrustful relationships with providers. For example, costs were noted as a key barrier, but most patients believed that if a provider prescribed a less-expensive generic medication, the generic would be less effective than its brand name counterpart. In fact, research has shown that reducing or eliminating costs improves medication adherence only slightly [2]; our findings provide a potential explanation for these small improvements. Other patients were concerned about incomplete disclosure of side effects or treatment options. Finally, some patients believed that their providers had made mistakes or had financial motivations, particularly when more than one antihypertensive drug was prescribed. Using shared decision making and decision support tools to engage patients early in the treatment decision-making process may alleviate some of these barriers by promoting frank discussion and improving patients’ trust in their providers. Decision support tool content may also act as a reminder to providers to discuss basic details they might overlook (such as the name of the drug) and more complex information (such as side effects) [34]. Patients may be prompted to ask questions they otherwise might be reticent to ask.

Our study has several limitations. The participants in our focus groups opted in, and because these patients self-selected, they may have held particularly strong views that were not representative of the larger patient population with incomplete PMA. It is likely that these patients represent those with the highest barriers to PMA. However, other studies have documented similarly poor patient–provider
relationships, costs, fear of side effects and complexity of treatment as adherence barriers [9]. Focus group patients reported receiving diagnoses of hypertension both recently and during the more distant past. Patients’ recall of the hypertension diagnosis experience, and their subsequent behaviors, might be impacted by hypertension duration. Although we focused on hypertension, a common problem [5], specific decision support tool content needs to be tailored to a given clinical condition. However, we believe that our findings and the themes outlined here are relevant to other disease settings. Finally, regardless of the communication enhancement strategy suggested—whether decision support tools or motivational interviewing, for example—some providers will not be interested in collaborative relationships with their patients.

Previous studies and successful interventions to improve medication adherence have typically focused on barriers such as costs, forgetfulness and simplifying dosing regimens [2, 39]. Our findings suggest that, while such interventions are important to sustaining medication adherence [2, 9, 40], they are unlikely to fully address the problem of PMA, so alternative approaches like shared decision making with decision support tools, for example, are needed to engage patients as well as their providers. Decision support tools may present a forum to establish provider credibility and patient trust prior to and at the point of prescribing an antihypertensive medication, thus improving PMA.

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Conflict of interest statement

Drs. Fischer and Polinski report receiving research support from CVS Caremark for unrelated studies of medication adherence. The remaining authors have no conflicts of interest, financial or otherwise, to disclose.

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### Appendix I. Antihypertensive medications

#### ACE inhibitors
- Benazepril
- Captopril
- Enalapril
- Fosinopril
- Lisinopril
- Moexipril
- Perindopril
- Quinapril
- Ramipril
- Trandolapril

#### Angiotensin Receptor Blockers (ARBs)
- Candesartan
- Eprosartan
- Irebsartan
- Losartan
- Olmesartan
- Telmisartan
- Valsartan

#### ACE and CCBs combinations
- Benazepril/amlopidine
- Enalapril/diltiazem
- Enalapril/felodipine
- Trandolapril/verapamil

#### Alpha blockers
- Doxazosin
- Prazosin

#### Beta blockers
- Acetamol
- Atenolol
- Betaxolol
- Bisoprolol
- Carteolol
- Carvedilol
- Esmolol
- Labetalol
- Metoprolol succinate
- Metoprolol tartrate
- Nadolol
- Penbutolol
- Pindolol
- Propranolol
- Sotalol
- Timolol

#### Thiazides
- Bendroflumethiazide
- Benzthiazide
- Chlorothiazide
- Chlorthalidone
- Cyclothiazide
- Hydrochlorothiazide
- Hydroflumethiazide
- Indapamide
- Methyclothiazide
- Metolazone
- Polythiazide
- Quinethazone
- Trichlormethiazide

#### Calcium channel blockers (CCBs)
- Diltiazem
- Mibefradil
- Verapamil
- Amlodipine
- Bepridil
- Felodipine
- Isradipine
- Nicardipine
- Nifedipine
- Nisoldipine

#### Combination CCB and statin
- Amlodipine/atorvastatin

#### Combination ARBs and diuretics
- Candesartan/hydrochlorothiazide
- Eprosartan/hydrochlorothiazide
- Irbesartan/hydrochlorothiazide
- Losartan potassium/hydrochlorothiazide
- Olmesartan/hydrochlorothiazide
- Telmisartan/hydrochlorothiazide
- Valsartan/hydrochlorothiazide

#### Beta blockers and diuretics
- Bendroflumethiazide/nadolol
- Chlorthalidone/atenolol
- Hydrochlorothiazide/bisoprolol
- Hydrochlorothiazide/labetalol
- Hydrochlorothiazide/metoprolol tartrate
- Hydrochlorothiazide/propranolol
- Hydrochlorothiazide/timolol