RESEARCH REPORT

Improving Chronic Illness Management in Harlem

Leveraging Community Health Coaches to Address the Challenge of Medication Management

Elaine Waxman, Megan Thompson, and Laudan Y. Aron
URBAN INSTITUTE

Manmeet Kaur, Jamillah Hoy-Rosas, and Elsa Haag
CITY HEALTH WORKS

October 2019
ABOUT THE URBAN INSTITUTE
The nonprofit Urban Institute is a leading research organization dedicated to developing evidence-based insights that improve people's lives and strengthen communities. For 50 years, Urban has been the trusted source for rigorous analysis of complex social and economic issues; strategic advice to policymakers, philanthropists, and practitioners; and new, promising ideas that expand opportunities for all. Our work inspires effective decisions that advance fairness and enhance the well-being of people and places.
# Contents

## Acknowledgments

## Improving Chronic Illness Management in Harlem

- **Introduction**
  - Chronic Disease in the United States
  - Effective Chronic Care Delivery
- The Reality of Care Delivery and Medication Management
- Effective Medication Management Strategies
- Health Coaching As a Patient-Centered Intervention
- Leveraging Community Support: The City Health Works Model
  - Client Characteristics, Challenges, and Escalations
- Medication-Related Escalations
- Material Hardship and Medication Management
- Implications for Policy and Practice
  - Insights for the Field
- Conclusion

## Notes

## References

## About the Authors

## Statement of Independence
Acknowledgments

This report was funded by the Rockefeller Foundation through the Janice Nittoli Practitioner Fellowship. We are grateful to them and to all our funders, who make it possible for Urban to advance its mission.

The views expressed are those of the authors and should not be attributed to the Urban Institute, its trustees, or its funders. Funders do not determine research findings or the insights and recommendations of Urban experts. Further information on the Urban Institute’s funding principles is available at urban.org/fundingprinciples.

We dedicate this report to the committed, hardworking community health workers across the globe, who play a vital role in bolstering the health of their communities and preventing crises. One conversation at a time, they enable their neighbors to feel more empowered and less alone when faced with health challenges.
Improving Chronic Illness Management in Harlem

Introduction

Since 2012, City Health Works in Harlem, New York, has hired clinically supervised, neighborhood-based health coaches to support low-income patients with chronic illnesses, helping them develop the knowledge, capabilities, and confidence to better manage their health. Medication management is a major focus in these coaches’ interactions with clients. Coaches frequently find discrepancies between the medications doctors prescribe and the medications present in the home. Additional complications arise from expired medications, nonprescription medications, patient misconceptions about medications, and challenges such as low literacy levels, poor eyesight, and food insecurity. As of March 2018, City Health Works coaches had worked with 776 clients, escalating 246 medical issues for 146 patients, including 122 urgent medication needs for 91 patients, potentially diverting costly trips to hospital emergency rooms. The often tangled interactions between health care providers, pharmacies, and patients can precipitate medication errors and escalations; preventing and mitigating these incidences are major benefits of community-based coaching programs like City Health Works.

This report investigates a key component of City Health Works’ health coaching: medication management. Drawing on City Health Works’ administrative data, we present the major reasons for medication issues, including those that required escalations to clinical supervisors or providers, as well as other actions and resolutions. We also discuss how community-based coaching can act as an extension of primary care by addressing medication management or adherence challenges that emerge in patients’ daily lives and are difficult to resolve through traditional primary care or pharmacy visits and how health coaching can develop patients’ self-management skills, including medication adherence. We conclude with some insights for the chronic care management field, particularly around medication management, based on City Health Works’ experiences.

Chronic Disease in the United States

Eighty-six percent of the nation’s $2.7 trillion annual health expenditures are for people with chronic conditions (Gerteis et al. 2014). These expenses are primarily for physical or mental health conditions lasting more than one year and often resulting in functional limitations and requiring ongoing
monitoring and treatment. Sixty percent of American adults have at least one chronic condition, and 42 percent have multiple chronic conditions (Buttorff, Ruder, and Bauman 2017). Many of the most common chronic diseases and conditions, including obesity, type 2 diabetes, and heart disease, are among the most costly and preventable health conditions. Preventing or managing these conditions, however, requires careful attention to diet, medication, and social determinants of health, such as stable housing, food security, access to transportation, and economic security.

How patients take medications and how they manage those medications alongside social determinants of health are major elements of chronic disease care and management. The share of US adults taking medications has steadily risen over the last several decades: about half (47 percent) of US adults take at least one prescription drug and about a quarter (22 percent) take three or more (National Center for Health Statistics 2017). For people over age 65, 77 percent of prescriptions are taken year round for chronic conditions, and though people ages 50 and over represent about a third of the US population, they account for 70 percent of all prescriptions (IQVIA Institute for Human Data Science 2017).

Nationally, about one in five prescriptions is never filled (Osterberg and Blaschke 2005). When prescriptions are filled, medication adherence—taking medications at the recommended time, dosage, frequency, or over the recommended duration—is an ongoing challenge for patients living with chronic conditions, as well as their providers. Nonadherence to medication regimens is associated with higher rates of hospital admissions, increased morbidity and mortality, suboptimal health outcomes, and increased health care costs, estimated at an extra $100–300 billion each year (DiMatteo 2004; Iuga and McGuire 2014; Viswanathan et al. 2012).

**Effective Chronic Care Delivery**

The current US health care system was built around treating acute illness rather than chronic conditions. Thus, building effective chronic care delivery requires restructuring the system and strengthening the relationship between patients and the health system to better support patients in continuously managing their condition(s).

The Chronic Care Model, first advocated for by Edward Wagner as a multipronged strategy for improving care for patients living with chronic illness, argues that for the patient-provider relationship to be productive and improve outcomes, health systems must reconfigure ambulatory care systems to address chronically ill patients’ ongoing needs and concerns (Coleman et al. 2009; Wagner 1998). The model emphasizes the following:
- Fostering planned, team-oriented care delivery, particularly among primary care teams increasingly occupied with caring for older, chronically ill patients.
- Educating and empowering patients living with chronic disease to serve as their “self-manager” at home, bolstered by community supports.²
- Building provider skill and expertise, including implementing evidence-based guidelines for chronic care management.
- Enhancing clinical information systems to facilitate coordinated, consolidated communication among care team members and across patient encounters (e.g., between inpatient care and different ambulatory settings).

The Chronic Care Model has been widely adopted for improving care delivery and has been integrated into current concepts of a patient-centered medical home. The model centers the primary care provider as a care coordinator and prioritizes integrating services that may address a range of patient needs, such as pharmacy, patient education and coaching, specialty care, and behavioral health services. Integrated care delivery reduces the patient’s onus to manage disconnected outpatient, inpatient, pharmacy, and other care management interactions and facilitates a more intentional focus on building patient self-management capacity and creating an informed and activated patient. And because a patients’ self-management of their condition(s) leads to better outcomes, health care systems are being challenged to better support patients outside the clinical setting.

The Reality of Care Delivery and Medication Management

Health systems across the country continue to grapple with better ways to deliver quality and cost-effective care to patients with chronic illness. Medication is often an important strategy for treating chronic illness, but some estimate that at least half of patients with chronic health conditions have inadequate medication management (Brown and Bussell 2011; Lin et al. 2010). This largely owes to the fragmented health care environment. For patients with multiple conditions and medications, the number and type of medical providers often increases, increasing the risk of miscommunication and errors (Buttorff, Ruder, and Bauman 2017). This risk can be particularly acute in large urban environments (Cancino 2017); some providers’ large volume of patients can reduce their ability to adequately support patients, even in team-oriented environments (Altschuler et al. 2019).
Poor medication management and medication errors can have life-threatening consequences. Adverse drug events account for nearly 700,000 emergency department visits and 100,000 hospitalizations per year. One study of 661 patients in outpatient care revealed that 25 percent experienced adverse drug events; 13 percent were serious, 28 percent ameliorable, and 11 percent preventable. Of ameliorable events (ones that were deemed not preventable but where the severity of the problem could have been reduced with different actions), 63 percent related to a physician’s failure to respond to a medication-related symptom, and 37 percent related to the patient’s failure to inform the physician of symptoms (Gandhi et al. 2003).

Various factors contribute to medication errors, problems with medication adherence, and adverse drug events (table 1). These include poor communication between multiple providers, clinics, and pharmacies; insurance errors; and patient factors such as knowledge, memory, and cognitive impairment (Allen et al. 2016; Gellad, Grenard, and Marcum 2011).

| TABLE 1 |
| Health System and Patient Factors That Contribute to Medication Errors and Nonadherence |
| Health system |
| Refill never submitted to pharmacy or given to patient |
| Wrong dose or device prescribed |
| Poor relationship with patient/misunderstanding of patient’s socioeconomic environment |
| Lack of knowledge about patient’s condition(s) |
| Prescription for paired medications/devices lacking |
| Managing multiple medication regimens simultaneously |
| Managing multiple complex conditions simultaneously |
| Pharmacy errors |
| Insurance issues |
| Lack of cultural competence among providers |
| Racial/ethnic disparities in access to care |
| Patient |
| Knowledge and understanding of condition(s) |
| Health literacy |
| Forgetfulness |
| Medication delivery device confusion |
| Uncertainty over adherence instructions |
| Refill process confusion |
| Insurance issues |
| Managing multiple medication regimens simultaneously |
| Managing multiple complex conditions simultaneously |

Sources: City Health Works escalation data; Allen et al. (2016); and Gellad, Grenard, and Marcum (2011).
Note: Health systems include physicians, pharmacies, clinicians, or insurance.

Medication management for patients living with multiple chronic conditions and socioeconomic stressors is particularly challenging: many patients require multiple medications and medication delivery devices and must navigate a complex system of providers, pharmacies, and insurance companies. In vulnerable populations, medication adherence rates tend to be lower than in other
groups because of social determinants of health such as economic insecurity, low literacy levels, limited English proficiency, poor mental health, cost barriers, and comorbidity (Aspden et al. 2007). Advanced age and certain illnesses that cause cognitive impairment or forgetfulness may also increase the likelihood of medication adherence issues.

Though clinical settings (Barker et al. 2002; Brady, Malone, and Fleming 2009; He et al. 2017), including pharmacies (Friedman et al. 2007; Murray et al. 2009), are making greater attempts to improve medication management, much work remains. Some have called for “correct medication lists,” which would require reconciling medications for patients seeing multiple clinicians, deprescribing medications when they are no longer needed or appropriate, and coordinating with outside entities such as pharmacies and electronic medical records companies (Rose, Fischer, and Paasche-Orlow 2017). However, the health care system’s systemic limitations, such as fragmentation of services, limited communication among service providers, and little time devoted to patient education and support, contribute to poor medication oversight and management.

Many patients, especially those managing multiple chronic conditions and social, economic, or educational challenges, need greater support and ongoing education to manage multiple medications in their homes. They may also need help coping with other self-care and management skills, such as monitoring their blood sugar, planning and preparing meals, managing depression or anxiety, and coping with financial challenges, which may involve forgoing meals, medications, or both (Aspden et al. 2007). Differences in cultural norms and beliefs may influence health and health-related behaviors, and a lack of cultural competence among providers may undermine the effectiveness of patients’ interactions with the health care system. Racial and ethnic disparities in access to care can also hamper patients’ receipt of needed support for chronic illness. Relatively few interventions have investigated how to build patients’ capacity to manage medications at home, especially when barriers they face are not perceived as an obvious “medical issue” (e.g., the ability to afford medicine, health literacy and/or numeracy, financial barriers, and family violence).

Effective Medication Management Strategies

Most research has focused on strategies designed to address health care system-level weaknesses, such as computerized tracking systems, in-office reconciliation programs, and pharmacy consultations. Though rigorous studies are still needed, several strategies have proved promising:
- **Computerized physician order entry systems.** These electronic prescribing and ordering systems may reduce medication errors and costs by facilitating communication between doctors’ offices and pharmacies (Koppel, Metlay, and Cohen 2005). Research shows these systems can increase physicians’ adherence to prescribing instructions, though physicians may frequently ignore alerts regarding potentially harmful drug combinations (Eslami, Abu-Hanna, and de Keizer 2007).

- **In-office reconciliation programs.** In these programs, patients come into the office to discuss their medication regimen (Varkey, Cunningham, and Bisping 2007), typically during major health events or transitions of care. Though medication reconciliation is relatively simple, translating medication reconciliation information across the fragmented health care system is complicated and prone to error (Barnsteiner 2008).

- **Pharmacist intervention.** During inpatient stays, pharmacist intervention can dramatically reduce medication errors by managing drug protocols and adverse drug reactions, as well as having pharmacists participate in nurses’ daily rounds (Bond, Raehl, and Franke 2012; Scarsi, Fotis, and Noskin 2002). Evidence regarding pharmacist intervention in outpatient settings is limited, but one study found pharmacist intervention with outpatients with cardiovascular disease significantly reduced medication error and adverse drug events (Murray et al. 2009).

Though these systemic approaches to improving patients’ medication management are promising, they fail to reach patients where most self-management issues occur: at home. This is where many patient-level factors, such as health literacy, cognitive ability, and environment, play out (Bailey, Oramasionqu, and Wolf 2013; Gonzalez, Tanenbaum, and Commissariat 2016). Some effective approaches to improve medication self-management have targeted health literacy and psychological interventions to address patient self-efficacy (Bailey, Oramasionqu, and Wolf 2013; Gonzalez, Tanenbaum, and Commissariat 2016; Gregg, Callaghan, and Hayes 2007; Mayberry and Osborn 2012; Sarkar, Fisher, Shillinger 2006). Another approach with inconsistent results relies on technology devices for medication reminders (Choudhry et al. 2017; Dayer et al. 2014; Hall et al. 2014).

Bridging the gap between medication management in health care systems and patients’ homes requires additional research, but emerging evidence shows community-based health workers can help address the challenges patients encounter in the community, including medication management (Hartzler et al. 2018).
Health Coaching As a Patient-Centered Intervention

One strategy for building patient self-management capacity is health coaching by people who are trained and familiar with or come from the community; can meet with people regularly at their home or in their neighborhood; help the patient build knowledge, skills, and confidence; and serve as a bridge between patients and providers (Cook, Render, and Woods 2000; He et al. 2017; Kawamoto et al. 2005).

Outside the US, research has found that community health workers improve patient health literacy, adherence, and outcomes for a range of chronic conditions, including tuberculosis, HIV and AIDS, and other infectious diseases (Chowdhury et al. 1997; He et al. 2017; Schneider, Hlophe, and van Rensburg 2008).

In the US, studies have shown that community health workers help patients manage their conditions through care coordination, assistance navigating the fragmented health care system, goal setting, helping them understand healthy lifestyles, providing support and education for stress management, and helping them access other resources and services (Allen et al. 2016). Community health workers can serve as an extension of primary care by helping physicians stay in regular contact with patients and providing patient-specific assessments and recommendations (Kawamoto et al. 2005).

In recent years, a growing body of evidence has indicated that community health workers can play a role in creating feedback loops to providers and patient care teams and helping escalate issues related to the patient’s medication regimen, adverse drug effects, and other concerns to a physician (Aspden et al. 2007; Gibbons and Tyus 2007; Hoffmann and Rohe 2010). These studies have also found community health workers improve doctors’ treatment adjustments and increase patients’ knowledge and self-management (Lin et al. 2010; Kangovi et al. 2018; Kawamoto et al. 2005). However, evidence on community health worker roles in improving outcomes has been complicated by the lack of standardization of models across the field.10
Leveraging Community Support: The City Health Works Model

Since 2012, City Health Works, a nonprofit organization based in Harlem, New York, has recruited and trained coaches from the community to support people with chronic conditions who have been referred by providers and can benefit from improved self-management and health outcomes. City Health Works coaches are trained to support people living with a range of diet, cardiovascular, and pulmonary chronic conditions, including diabetes, hypertension, congestive heart failure, and asthma. Until 2015, most patients received coaching for diabetes, but 95 percent of these patients had more than one chronic condition.

Coaches follow an evidence-based curriculum over a three-month period, meeting weekly with patients and serving as an on-call resource. After three months, coaches and their clients continue to maintain biweekly to monthly contact for an additional nine months, combining telephone calls and in-person visits, depending on the client’s preferences and needs (box 1). A clinical manager supervises and consults with coaches when questions arise that fall beyond their expertise or practice. Clinical managers are typically registered nurses and must be certified diabetes educators. The health coach supervisors have weekly to biweekly telephone or in-person case reviews with each coach and communicate daily via City Health Works’ custom software, email, and phone system.

BOX 1
Timeline of City Health Works Phases and Assessments

Source: City Health Works.

In some cases, the clinical manager may determine that an issue should be escalated to the patient’s primary care provider for further action. Escalations may be for issues with medications, medical
equipment, appointment scheduling, insurance, or urgent symptoms (e.g., unsafe blood pressure or blood glucose levels). The following analyses focus on experiences of clients who incurred at least one medication-related escalation during their engagement with City Health Works coaching, meaning a coach assessed a patient’s issue and decided it required the attention of a clinical supervisor or the client’s health care provider.

Client Characteristics, Challenges, and Escalations

We examine administrative data for all City Health Works clients enrolled between 2012 and March 2018. For medication management escalations, we examine information on client demographics; why escalations occurred, what occurred in response, and the likelihood that an emergency department visit was prevented. Valuable insights and illustrative stories from City Health Works health coaches shed light on the program's approach and outcomes and how community health workers are an important addition to a patient’s care team.11

CLIENT CHARACTERISTICS

Table 2 presents descriptive data on City Health Works clients overall and on those for whom a medication-related escalation occurred during the period we examined. Women account for just under two-thirds of all City Health Works clients, but they represent a slightly greater share of clients who have experienced a medication escalation (74 percent). Most clients are over age 50; 25 percent are in their 50s, another 27 percent in their 60s, and 24 percent are in their 70s. Those with medication-related escalations are somewhat older, with a third over age 70. Eighty-three percent of clients do not have a college degree, and an even greater share (92 percent) of those with one or more medication-related escalations does not have a college degree. Though 40 percent of all clients speak a primary language other than English (mostly Spanish), an even higher share, closer to 50 percent, of those experiencing medication-related escalations are not native English speakers. Three-quarters of all City Health Works clients have diabetes, but the corresponding figure for those with medication-related escalations is 85 percent.
TABLE 2
Characteristics of City Health Works Total Population and Clients Experiencing Medication-Related Escalation

Percent

<table>
<thead>
<tr>
<th>Total population distribution (N = 776)</th>
<th>Distribution of clients experiencing medication-related escalation (n = 91)</th>
<th>Rate of medication-related escalation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>70</td>
<td>74</td>
</tr>
<tr>
<td>Men</td>
<td>30</td>
<td>26</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;50</td>
<td>16</td>
<td>14</td>
</tr>
<tr>
<td>51–60</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>61–70</td>
<td>27</td>
<td>26</td>
</tr>
<tr>
<td>71–80</td>
<td>24</td>
<td>30</td>
</tr>
<tr>
<td>81+</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Primary language(s)a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>English or English plus another language</td>
<td>58</td>
<td>48</td>
</tr>
<tr>
<td>Spanish</td>
<td>40</td>
<td>48</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Primary City Health Works program</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Diabetes</td>
<td>76</td>
<td>85</td>
</tr>
<tr>
<td>Hypertension</td>
<td>13</td>
<td>9</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Source: City Health Works.

Notes: Because of rounding, percentages may not add to 100.

Excludes some missing data on clients’ language only for the total population.

Medication-Related Escalations

Among the 122 medication-related escalations reported by City Health Works health coaches over the study period, most (72) occurred in the first three months after enrollment, when clients are integrated with the program and benefiting from intensive services and supports (figure 1). Twenty-six of the 122 medication-related escalations occurred between months three and six, and just 17 occurred in the final six months of the program, when the coach and client primarily interact via telephone biweekly or monthly.
Ninety-one clients experienced these 122 medication-related escalations. As shown in figure 2, the most common reasons for an escalation were

1. medication refills or supply (59 medication escalations), suggesting this is a powerful point for intervening and preventing problems;
2. medication error or a concern about how to adhere to the regimen (32 medication escalations);
3. medical equipment prescription issues (22 medication escalations); and
4. urgent symptoms related to medication (9 medication escalations).
Boxes 2 through 5 demonstrate examples of medication-related escalations and the processes for addressing them. The diversity of issues faced by City Health Works clients confirms research literature on this topic, and City Health Works’ clinical review suggests 37 percent of the 122 escalation events would have likely resulted in an emergency room visit if the health coach had not escalated the medication issue to her clinical supervisor.

The 59 escalations related to medication refills or supply issues, which accounted for 48 percent of all medication-related escalations, typically resulted from a client running out of medication and needing a refill (75 percent), miscommunication between the doctor’s office and pharmacy (24 percent), or not having a necessary prescription (10 percent; data not shown). Several instances show that a client needed a refill but could not contact her doctor to get it. Others, including the example in box 2, reveal a system issue in which the doctor’s office miscommunicated instructions or forgot to send the prescription to the pharmacy. Some medication refill escalations were minor issues the coach helped coordinate, like getting a refill before the client ran out of medication. Other more urgent medication refill issues, such as a client running out of medication that stabilizes her blood sugar levels, required immediate action from the health coach to escalate the issue to the physician the same day.
The 32 escalations related to medication error or adherence include errors in how doctors prescribed or clients took medication. Not quite half of the most common adherence-related escalations involved client confusion over the medication instructions or dose, causing the patient to either stop taking her medication or take it inaccurately (too little or too much of a dose; data not shown). For clients relying on medication to regulate their blood sugar or control their asthma, for example, medication error or adherence issues could cause serious health issues, such as an asthma attack or a hypoglycemic (low blood sugar) or hyperglycemic (high blood sugar) episode. Such events can result in emergency room visits or hospitalization (Mazurek and Syamlal 2018; Wang et al. 2015). Some medication error or adherence issues, such as client nonadherence because of discomfort with injecting insulin or stomach distress caused by medication, led to adverse drug events (box 3).
BOX 3
Client Escalation Example: Discontinuing Medication Because of Side Effects

During a coaching visit, the client told the coach that she had stopped taking her diabetes treatment medication because it upset her stomach. The client had a blood glucose reading of over 300 mg/dl.

The health coach notified the health coach supervisor, who escalated the issue to the RN coordinator at the client’s doctor’s office, who then informed the primary care physician.

The primary care physician recommended the client increase her insulin and come into the diabetes clinic for an urgent visit.

Source: City Health Works.
Notes: RN = registered nurse. The recommended range for blood glucose for good diabetes management is between 70 mg/dl and 130 mg/dl before meals and less than 180 mg/dl two hours after meals. See “Tight Diabetes Control,” American Diabetes Association, June 7, 2013, http://www.diabetes.org/living-with-diabetes/treatment-and-care/blood-glucose-control/tight-diabetes-control.html.

Medical equipment prescription issues accounted for 22 of the 122 medication escalations. Half of these medical equipment prescription escalations typically occurred when a medical device or equipment did not work properly. Other common reasons for escalation included refill issues or the physician failing to provide the client with a prescription for necessary equipment to take her medication, such as prescribing insulin without prescribing the lancets or test strips used to test blood glucose levels (box 4); the coach coordinating services for the client to receive a needed mobility device, such as a walker, wheelchair, or bathroom chair; or the coach helping the client contact her physician. Most medical equipment prescription escalations were not urgent escalations and were unlikely to have resulted in an emergency room visit.
BOX 4
Client Escalation Example: Provider Had Not Prescribed Needed Medical Equipment

Client reported that she was not prescribed lancets and test strips after requesting them at a recent doctor’s appointment. The client discovered this when she went to the pharmacy and the lancets and test strips were not e-prescribed.

The health coach contacted the health coach supervisor, who then contacted the clinical site about the issue.

The clinical site faxed the scripts to the pharmacy.

Source: City Health Works.
Note: RN = registered nurse.

The final escalation type concerns urgent symptoms related to medication (box 5), which accounted for 9 of the 122 medication escalations. Most of these urgent symptoms arose when, during a check-in with the client, the coach noted that the client reported extremely high blood pressure readings, having too low or high blood glucose levels, or experiencing adverse drug events that required immediate attention. These escalations typically resulted from recent changes to a client’s medication regimen that caused adverse drug events, the client running out of medication, or a client forgetting to take her medication.
Material Hardship and Medication Management

While untangling the many challenges clients face in managing medication, coaches often identify material hardships, such as food insecurity and housing instability, as reasons clients may not adhere to medication regimens. Providers can rarely see these challenges, because patients may be reluctant to disclose their personal struggles; even safety net providers do not always have the time and training to effectively facilitate conversations with patients to identify and troubleshoot their hardships. Because coaches meet with clients in their homes or other community settings and are familiar with the challenges neighbors face in their daily lives, they are often better positioned to identify when material hardship contributes to poor health outcomes. Nevertheless, these issues do not always emerge when tracking escalations, because their resolution may not involve a clinician or coaches may learn about these issues after the fact.

City Health Works coaches were asked by their clinical supervisors to identify concrete examples among their recent clients of how material hardship jeopardizes patients’ ability to effectively manage their illness. In one case, a client was working but had low earnings, and though he received Supplemental Nutrition Assistance Program (SNAP) benefits, he could not stretch them to support his monthly food budget. At the end of the month, he ran out of food but still took prescribed insulin
injections. He experienced a severe hypoglycemic episode at his job and was rushed to the emergency room.

Another client stopped taking her medicine when her apartment building experienced a gas leak and a prolonged utilities shut off, and she was unable to prepare full meals for an extended period. Taking her oral medications without sufficient food resulted in significant symptoms, including vomiting, so she discontinued taking her medication. Consequently, her blood glucose rose to unhealthy levels, requiring clinical intervention.

A third client continuously struggled to maintain a diet that could adequately manage her illness. The client had limited income, and though she received SNAP benefits, they could not compensate for her limited resources. Research on the inadequacy of SNAP benefits shows that the average cost of a low-income meal in New York City is 113 percent higher than the maximum per meal benefit SNAP provides.13 Her daily challenges extended beyond affording food; she dealt with bug infestation, had received eviction notices, and had limited literacy skills, all of which contributed to self-management challenges.

Community-based coaches can advocate for resources and help clients troubleshoot barriers and have the proximity to identify competing demands that may erode patient compliance with clinical recommendations, but chronic deprivation can diminish the effectiveness of medical treatment. Though social determinants of health are increasingly recognized as an essential factor in improving health outcomes, without robust supports based in the community, many patients will likely continue to face significant barriers to adherence.

Implications for Policy and Practice

Better medication management in both clinical and home settings is necessary. Many groups, such as the Institute for Safe Medication Practices, the American Society of Health-System Pharmacists, and the National Patient Safety Foundation, work to improve research, policy, and practice in this area. Currently, navigating and mitigating systems-level medication errors falls on patients and families, and often these systems-level breakdowns are not apparent until a patient, family member, or health coach contacts a pharmacist or health provider with questions or concerns about a medication. Capturing this real-world feedback and redesigning systems and procedures to minimize medication errors can drive continuous learning and improvement within health and pharmacy systems.
Even without these systems-level issues, patients would still require education, monitoring, and support around medication use for complex chronic conditions. Patient support is not only integral to managing the complexity of chronic illnesses such as diabetes but also helps ameliorate financial pressures and other sources of instability in many patients’ and families’ lives, especially those with low incomes. Patients need support to understand what medications they need to take, obtain and refill medications, take the right doses at the right times and in the right ways, and manage any side effects or comorbid health conditions. Additional complications and management needs arise when patients are prescribed multiple medications or need to adjust medication regimens following a hospitalization or an acute episode. Many social and economic challenges, such as food insecurity, housing instability, family violence, social isolation, low literacy levels, or English language barriers, can further complicate people’s abilities to follow medication regimens (Kushel et al. 2006; Lor et al. 2019; Patel et al. 2017).

Insights for the Field

Health coaching can address significant challenges that people living with chronic conditions often face. City Health Works’ experience with regularly supporting vulnerable clients with medication management and sometimes escalating these challenges suggests barriers arise from multiple sources:

- Many patients lack the self-management education and coaching around medication and disease that could empower them to navigate their conditions more effectively.
- Patient care is fragmented across disconnected ambulatory, hospital, specialist, pharmacy, and social service providers. Often, no dedicated care team assists patients across their health journey, and miscommunication or poor coordination occurs between parts of the system on which the patient relies, such as the clinic and the pharmacy.
- Providers often lack insight into the challenges their patients face in their daily lives, including with literacy, numeracy, financial stress, and other competing demands like caregiving. Providers may assume a patient is simply being noncompliant with a recommended regimen without understanding the complexity of the reasons for their lack of adherence.

Building from the insights from Community Health Works’ experience, we identify several opportunities the field may consider for improving responsiveness to patient needs.

OPPORTUNITIES FOR CLINICAL PRACTICES

Medical practices may need to create new workflows to more efficiently respond to patients’ calls about medication concerns and questions. Though these improvements may help all patients, they may
be particularly valuable for those managing both complex chronic diseases and material hardships. Strategies could include

- providing a phone option to redirect a call from the general phone line to a dedicated, on-call registered nurse who can quickly address concerns;
- hiring a dedicated pharmacist, or establishing a pharmacy partner, to be on call for timely response to medication-related calls; or
- contacting patients proactively to remind them to bring medication lists to appointments to verify and correct the list in the electronic medical record and document over-the-counter medications alongside those prescribed by clinicians.

OPPORTUNITIES FOR HEALTH CARE PROVIDERS AND PAYERS

Many medication-related escalations arise because patients lack knowledge about their medications or disease processes, are confused by the complexity of their care plan, or miscommunicate with their providers. To prevent these escalations, we suggest providers and payers do the following:

- Give patients with a chronic illness comprehensive and accessible resources to teach them the basics of their condition. City Health Works has adapted evidence-based content to create comprehensive, low-literacy-friendly booklets providers can share with patients.

- Provide comprehensive, one-on-one chronic disease self-management education and coaching to patients with complex chronic diseases, emphasizing self-efficacy and medication knowledge for patients at a higher risk of medication-related escalations. Patients who are older, have two or more chronic illnesses, low literacy levels, or physical or cognitive impairments are most vulnerable to medication-related escalations and most need dedicated health coaching and written guides on disease education. Though coaching can benefit clients from all backgrounds, clients with low incomes, who have limited English proficiency, or who may already face disparities in accessing health care may particularly benefit from a coach’s more proactive support.

- Deliver educational coaching through health coaches who are well trained, supervised, and embedded into the care team at the primary medical practice. Alternatively, contract with community-based vendors, such as City Health Works, who provide neighborhood-based health coaching and are directly integrated with primary care teams to ensure alignment with a unified care plan and medication list.
- Identify a primary care provider or nurse practitioner who can ensure medication reconciliations are completed in coordination with the primary care provider’s plan. This should take place after any acute health event (i.e., hospital or emergency department visit), during a visit to a specialist, and annually with the primary care physician. Assigning a dedicated primary clinician is especially essential for patients with multiple medications.

- Forge more value-based contracts that incentivize providers to minimize fragmentation and encourage patient self-efficacy, thereby increasing medication adherence while decreasing spending.

PHARMACIST RECOMMENDATIONS
A pharmacy intervention, in coordination with a dedicated primary care team, can prevent many urgent medication issues by

- performing routine medication reconciliations, especially when a patient gets a new prescription, and sharing this information with the patient and provider;
- offering prescription home delivery;
- alerting providers when a prescription has not been filled so the provider can reach out to the patient;
- improving medication bottles’ readability to make dose, timing, and adherence easier for the patient;
- establishing more e-prescribing methods, such as computerized physician order entry, between providers and pharmacy; and
- making 90-day refills available for ongoing medications.

MEDICAL AND NURSING EDUCATION RECOMMENDATIONS
Medical and nursing education may not offer essential education around chronic disease self-management. Medical and nursing schools should integrate more curricula on

- teaching patients about self-managing chronic illness, specifically related to nutritional management, identifying symptoms, and motivational interviewing;
- integrating chronic disease educators into primary care teams (e.g., providers who have patients with diabetes could integrate certified diabetes educators and/or health coaches into the primary care team); and
providing field experience for students to learn from providers who coach and educate in patients’ homes.

Conclusion

Chronic disease self-management support is an evidence-based strategy that can improve health outcomes. Health coaching programs, such as City Health Works, can be powerful allies to both patients and health systems alike in tackling the persistent challenges of medication management. Not only can these programs help patients and families enjoy better health and avoid costly medical emergencies, they can also educate health providers and systems on how to better support patients and achieve better population health outcomes through redesigning and improving practices and systems. Though coaching is often characterized as meeting patients “where they are,” these programs can also help address the realities of fragmented medical teams by meeting providers where they are. Health coaches can also serve as an extension of primary care by codesigning effective systems of communication and escalation for patients with complex needs. Ultimately, locally hired, well-managed health coaches can provide critical supports and encouragement for vulnerable community members, educating and empowering them and bolstering the effectiveness of clinical care within the community, where people and families live and thrive.
Notes


2 The theory of self-efficacy proposes that patients’ confidence in their ability to perform health behaviors influences which behaviors they engage in. Thus, self-efficacy is a patient’s confidence in her ability to manage her health (Sarkar, Fischer, and Shillinger 2006).

3 Medication errors occur while using medications and can be caused by a person or the medical system, such as pharmacies or doctors’ offices (Aspden et al. 2007).

4 Adverse drug events are any mental or physical reaction or injury that results from medication. This could include dosing issues or allergic reactions (Aspden et al. 2007). For more on adverse drug events, see “Medication Errors and Adverse Drug Events,” Agency for Healthcare Research and Quality, Patient Safety Network, accessed March 1, 2019, https://psnet.ahrq.gov/primer/medication-errors-and-adverse-drug-events?q=/primers/primer/23.


7 Medication reconciliation is a formal process that typically occurs between physician and patient to create the most complete and accurate list of a patient’s current medications, adjusting and fixing the list in the patient’s medical record or medication orders (Barnsteiner 2008).

8 Health literacy is a patient’s ability to access, comprehend, and understand the basic health information and services needed to manage her health conditions and care effectively (Bailey, Oramasionqu, and Wolf 2013).


11 The Urban Institute obtained data provided by City Health Works through its Institutional Review Board process. We stripped all data of personal identifiers to preserve client confidentiality.

12 Aversion data is tracked by the clinical supervisor, who uses her best clinical judgment to determine if the client would have likely ended up in the hospital. Other aversions are more explicit, where the client mentions to her coach that she is going to the emergency room and the coach intervenes to address the issue without a visit.


References


About the Authors

Elaine Waxman is a senior fellow in the Income and Benefits Policy Center at the Urban Institute. Her expertise includes food insecurity, nutrition, the food assistance safety net, and social determinants of health disparities, as well as broader issues affecting low-income families and communities. Waxman is part of the leadership team coordinating the Institute’s From Safety Net to Solid Ground initiative and codirects the Institute’s cross-center initiative on the social determinants of health. Before joining the Institute, Waxman served for six years as the vice president of research and nutrition at Feeding America, where she oversaw research on food insecurity and nutrition, federal nutrition programs, the intersection of hunger and health, and the circumstances and experiences of individuals seeking charitable food assistance. She also helped develop community-based intervention models to address the needs of low-income, food-insecure families. She has coauthored numerous research and policy reports and articles in scholarly journals, including Applied Economics Perspectives and Policy, American Journal of Public Health, Health Affairs, Social Service Review, Journal of Hunger and Environmental Nutrition, Journal of Family and Economic Issues, and Journal of Food Law and Policy. She received her MPP and PhD from the University of Chicago, where she is a lecturer at the School of Social Service Administration.

Megan Thompson is a former research assistant in the Income and Benefits Policy Center. Her work focused on Temporary Assistance for Needy Families, food and nutrition issues, and microsimulation modeling. Previously, Thompson worked in the legislative affairs department at the Center on Budget and Policy Priorities and was an analyst at the Michigan Department of Community Health – Women, Infants, and Children Program. Thompson received a dual BA in comparative cultures and politics and in social relations and policy from Michigan State University and an MS in food systems and society from Marylhurst University.

Laudy Aron is a senior fellow in the Health Policy Center at the Urban Institute. Since joining Urban in 1992, she has spent over 25 years conducting research and policy analysis on a wide range of social welfare issues, including health and disability, education, employment and training, homelessness, and family violence. She directed and coedited a groundbreaking 2013 study for the National Research Council and Institute of Medicine, US Health in International Perspective: Shorter Lives, Poorer Health, which found a large and growing US “health disadvantage” relative to other high-income countries. Her work focuses on how social and economic conditions shape health and well-being, and how social welfare programs (broadly defined) can best support healthy human development across the life course and over time and place. Throughout her career, Aron has conceptualized, designed, and fielded studies
that are of greatest use to policymakers, program officials, and other interested stakeholders. Her many publications include books, book chapters, journal articles, and opinion pieces on topics ranging from social determinants of health to urban education reform. From 2007 to 2012, she served as a senior program officer with the Division of Behavioral and Social Sciences and Education at the National Academy of Sciences and as director of policy research at the National Alliance on Mental Illness. Aron holds a BS in mathematics from McGill University and an MA in demography from the University of Pennsylvania.

**Manmeet Kaur** founded City Health Works in 2012 to create a business case for neighborhood-based health coaching delivered by community health workers. City Health Works has become a national example of how to deploy locally hired care teams to improve health, reduce spending, and create rewarding jobs. It has been featured in *Politico*, *PBS NewsHour*, *the Economist*, *NPR*, *Crain’s*, and elsewhere. Before launching City Health Works, Kaur worked with local and multicountry community workforce initiatives in South Africa, India, and New York City. In her time abroad, Kaur saw the potential for applying best practices in from low-income countries to the US. Her work emphasizes the link between fostering high-quality operations and high-quality jobs. Kaur served as the inaugural Janice Nittoli Practitioner Fellow at the Urban Institute and was a Draper Richard Kaplan social entrepreneur and a GLG Social Impact Fellow. She earned a BA from Barnard College and an MBA from Columbia University.

**Jamillah Hoy-Rosas** is a senior health care professional who has worked in nutrition and public health for over 18 years. Hoy-Rosas specializes in all areas of health care service delivery, particularly curriculum and program design, quality improvement, and compliance. She has worked in clinical care coordination, medical case management, medical nutritional therapy, maternal and child nutrition, and worksite wellness. She is a trained lifestyle coach for the National Diabetes Prevention Program, a US diabetes conversation map program facilitator, and an asthma care specialist. Hoy-Rosas is the chief health officer at City Health Works. In this role, she directs the design and delivery of the organization’s health coaching and care coordination services for diabetes, hypertension, asthma, and congestive heart failure and oversees the hiring, training, supervision, and ongoing support of the care delivery teams. Hoy-Rosas also oversees grants and partnerships with health systems, managed care organizations, medical practices, and community-based organizations. Hoy-Rosas is a 2018 Clinical Scholars Fellow with the Robert Wood Johnson Foundation and a registered dietician. She received her bachelor’s degree in biological basis of behavior from the University of Pennsylvania and her master’s degree in public health nutrition at New York University.
Elsa Haag is a law student at Duke University School of Law and is committed to advocating for health equity and environmental justice. She worked at City Health Works first as an operations analyst, managing quality-improvement projects and designing and implementing a care coordination and health record database to support health coaches, care managers, and clients. She then worked as City Health Works’ policy and research associate, working on policy initiatives; managing research studies with health system partners; and writing about City Health Works for press, partners, funders, and other stakeholders. Before City Health Works, Haag worked at the Institute for Public Health Innovation on their community health worker program, Positive Pathways, and interned at the Environmental Protection Agency in the Office of Children’s Health Protection. Haag received a BA with honors in neuroscience from Earlham College.
**Statement of Independence**

The Urban Institute strives to meet the highest standards of integrity and quality in its research and analyses and in the evidence-based policy recommendations offered by its researchers and experts. We believe that operating consistent with the values of independence, rigor, and transparency is essential to maintaining those standards. As an organization, the Urban Institute does not take positions on issues, but it does empower and support its experts in sharing their own evidence-based views and policy recommendations that have been shaped by scholarship. Funders do not determine our research findings or the insights and recommendations of our experts. Urban scholars and experts are expected to be objective and follow the evidence wherever it may lead.