

## ORIGINAL RESEARCH

## Facilitators and Barriers to Care Coordination in Patient-centered Medical Homes (PCMHs) from Coordinators' Perspectives

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**Background:** Care coordinators are increasingly featured in patient-centered medical home (PCMH) projects, yet little research examines how coordinators themselves define and experience their role. This is the first study describing experiences of care coordinators across the US from their own perspectives.

**Methods:** This qualitative study used a 5-month private, online discussion forum to gather data from 25 care coordinators from PCMH practices representing diversity in practice size, setting, and type. Participants answered questions and interacted with one another, creating an online social learning collaborative while allowing for data collection for research.

**Results:** Coordinators identified barriers and facilitators in their work at the organization/system level, the interpersonal level, and the individual level. Some factors emerged as both barriers and facilitators, including the functionality of clinical information technology; the availability of community resources; interactions with clinicians and other health care facilities; interactions with patients; and self-care practices for mental health and wellness. Colocation and full integration into practices were other key facilitators, whereas excessive case loads and data management responsibilities were felt to be important barriers.

**Conclusions:** While all the barriers and facilitators were important to performing coordinators' roles, relationship building materialized as key to effective care coordination, whether with clinicians, patients, or outside organizations. We discuss implications for practice and provide suggestions for further research. (J Am Board Fam Med 2016;29:90–101.)

**Keywords:** Delivery of Health Care, Internet, Patient-centered Care, Primary Health Care, Qualitative Research

A guiding principle of the patient-centered medical home (PCMH) model is that patient care should be coordinated across the health care system and the patient's community.<sup>1</sup> Coordinated care has become increasingly necessary as the chronically ill

population grows and our health care system becomes more complex and fragmented.<sup>2</sup> Potential benefits of care coordination for both care quality and cost include reduced hospital admissions, improved quality of chronic disease management, improved patient satisfaction, and better access to specialty care.<sup>2–14</sup> However, there is a lack of consensus on what constitutes coordinated care and which coordination activities are most useful.<sup>2,15</sup> Over 40 definitions of care coordination exist, and many related terms are used interchangeably with *care coordination* (eg, collaborative care, continuity of care, disease management, case management,

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care management, and care or patient navigation).<sup>15</sup> The Agency for Healthcare Research and Quality defines care coordination as “the deliberate organization of patient care activities between 2 or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.”<sup>15</sup>

While studies have generally found positive effects of care coordination interventions, most focused on patients with a single disease and the use of care managers who are external to community practices.<sup>2</sup> Recent evidence calls into question the effectiveness of care coordination and chronic disease management programs that lack connections to patients’ primary care physicians.<sup>16,17</sup> In response, care coordinators are increasingly being implemented in primary care practices and featured in PCMH projects and accountable care organizations.<sup>21–23</sup> However, research examining how care coordinators are integrated in primary care settings and how they understand and experience their role is limited.<sup>21–24</sup> While previous articles describe activities of care coordinators, they do not include care coordinators’ viewpoints<sup>21,22</sup> nor more than 1 coordinator’s account<sup>23,24</sup> to aid in replicating and sustaining this role in primary care. The purpose of our research was to understand care coordinators’ perceptions about their roles in primary care practices and their experiences with barriers and facilitators to their work. Because the role of care coordinator in primary care is developing and relatively unstudied, we included in our research participants who self-identified as performing care coordination in primary care, regardless of their title.

## Methods

### Setting

This study used a private, asynchronous online discussion forum to gather data on care coordinators’ perceptions and experiences.<sup>25</sup> This forum allowed coordinators from diverse primary care settings across the United States to participate over several months without time restrictions, generating rich, detailed qualitative data.<sup>26,27</sup>

### Sample

Using the list of PCMH demonstration projects on the Patient-centered Primary Care Collaborative website ([www.pcpcc.org](http://www.pcpcc.org)), we identified practices with care coordinators and E-mailed a flyer to their medical directors to invite coordinators to participate. Using a snowball sampling approach, we also asked practices to circulate our study announcement to other programs using care coordinators. Given that the care coordinator role is still developing and prior research lacks consensus about how it is defined, we purposely chose to be broad and inclusive in our selection of participants. Our solicitation E-mail stated that participants must be “working as a care coordinator” in a primary care office. Since many terms are used interchangeably with *care coordinator* (eg, care manager, case manager, patient navigator),<sup>28</sup> people with these other titles who identified themselves as “coordinating care” in primary care offices also were eligible. Because our recruitment strategy relied on medical directors to invite potential participants, participants also had to be known within their practices as fulfilling the care coordinator role. Interested respondents completed a demographic survey, and we purposely selected participants from practices representing diverse practice sizes; settings (urban, suburban, rural); and types (academic, affiliated with a hospital or an integrated health system, community health center). Of 33 care coordinators who expressed interest, we enrolled 25 because the mean sample size of other online focus groups has been 12 to 14, with up to a 50% dropout rate.<sup>29</sup> Participants provided informed consent before the forum started. The institutional review board at Rutgers Robert Wood Johnson Medical School approved this study.

### Data Collection and Management

Our research team (3 sociologists and 1 family medicine physician) asked questions and stimulated interaction among coordinator participants. Participants answered questions, commented on other participants’ responses, and posed questions of their own, generating further group discussion. The forum was therefore an online social learning collaborative as well as a site for data collection for research.<sup>30</sup> To encourage participation, we used E-mail reminders, monthly \$100 gift card drawings, and incentive points corresponding to frequency and type of postings. The 3 participants with the most incentive points received

gift cards worth \$100, \$75, and \$50 at the conclusion of the forum.

Our preliminary semistructured interview guide was based on the organizational design framework.<sup>28</sup> As suggested by the Agency for Healthcare Research and Quality's technical review of care coordination,<sup>28</sup> the organizational design framework is a useful conceptual model to guide the development, implementation, and evaluation of care coordination interventions. In this model the care coordinator is the "good fit" that matches the demands of the setting and patients (coordination needs) with the coordinating mechanisms that facilitate information flow and information processing for coordinating activities. Some of the questions we posted asked respondents to describe a typical workday, how their position was created, how they identify patients in need of and providers involved in care coordination, how their position is integrated into the practice(s), the process of communicating and exchanging information, as well as some of their success stories (see the Appendix). Typically, we posted 1 question each week. With the exception of the initial "grand tour" question<sup>31</sup> ("Describe a typical workday"), we did not require respondents to answer every question, but allowed them to answer as they wished. The forum continued until all topics of interest had been posted and data reached saturation (5 months).

### **Analysis**

We monitored the online discussion daily, and after the conclusion of each thread of conversation, we imported text into ATLAS.ti (Atlas.ti Scientific Software Development GmbH, Berlin, Germany) for formal analysis. Our research team met weekly to analyze data using a grounded theory approach,<sup>32,33</sup> tagging text to identify emerging themes and generating follow-up questions for posting. We posted preliminary findings in a researchers' analysis blog where coordinators could build on or clarify ideas. As a result, coordinators were not just research subjects, but participants engaged in shaping the findings.<sup>34</sup> In addition, we met monthly with consultants (experts in qualitative methods, communication, and information technology) to discuss emergent findings. We then used a series of immersion-crystallization cycles to identify themes among the data and to compare and contrast these themes within cases.<sup>35</sup> The quotations included in this article illustrate our key findings.

### **Results**

Care coordinator participants were female, mostly white, between 41 and 60 years old, and working in their respective practices for <5 years. Most participants had either an associate's or bachelor's degree. Coordinators were roughly evenly distributed across practice types, settings, and sizes (Table 1).

A total of 25 participants answered the first question, and 17 continued to log in through the fifth and final month, with 13 continuing to post. We found few differences between respondents who dropped out of the study and those who continued posting until the end. These 2 groups were comparable in age, race, mean hours worked per week, practice type, and number of clinicians per practice. There were some differences in the racial makeup of the patient populations within practices served (participants who stayed through the end of the forum: 80% white; those who left: 61% white), as well as their education level (those who stayed were more likely to hold an RN or BSN degree).

#### **Care Coordinator Role**

Coordinators varied in how their role was defined, funded, and integrated within a practice. About half served all practice patients, working with any patient "identified by any staff member as needing additional assistance" (coordinator 25). Other coordinators focused on a specified disease or clinical target. At least 5 coordinators worked with patients covered by particular insurers or those identified by an insurance-based "chronic care risk score" (coordinator 17). Panel sizes ranged from 200 to 500. Some coordinators were fully integrated in a practice, huddling with physicians and meeting with patients, whereas others worked across multiple practices, sometimes geographically separated from practice members and patients. Funding for the coordinators' positions also varied; some were salaried by the practice, whereas others were supported by grants or pilot projects.

The most commonly mentioned job functions among our respondents were identifying patients in need of care coordination; outreach to patients by phone or mail; conducting face-to-face patient encounters; providing social support for patients; collecting, managing, and exchanging patient data; supporting physicians; and backing up clinical and administrative staff. These 7 categories of job activities seemed to represent a common core of the

**Table 1. Characteristics of Forum Participants, January–May 2012**

Characteristics	No.*
Participants	
Age, median years (IQR)	48.0 (15.0)
≤40	6
41–50	9
51–60	7
>60	1
Race	
Non-Hispanic white	19
Other	5
Educational level	
Associate’s degree	10
Bachelor’s degree	11
Master’s degree	3
Hours per week, median (IQR)	39.1 (3.9)
<40	4
≥40	20
Years in current practice, median (IQR)	2.8 (2.7)
<1	4
1–2	7
2.5–4	7
5–6	4
>6	2
Practice	
Practice type	
Private	6
Academic/residency	6
Community health center	7
Hospital affiliated/integrated system	6
Locale	
Urban	9
Suburban	9
Rural	7
Clinicians per day, median (IQR)	10 (13)
1–5	8
6–10	6
11–18	6
>18	5
Specialty	
FM	13
IM	4
FM and IM	2
Multispecialty	6
US region	
Northeast	11
South	3
Midwest	5
West	6

*Continued*

**Table 1. Continued**

Characteristics	No.*
Patient population	
Predominantly white	14
At least 25% minority	10

\*Some categories have missing data (respondents did not provide all requested information). IQR, interquartile range.

care coordinator role among our respondents. (See Table 2 for more details.)

**Barriers and Facilitators**

The barriers and facilitators to care coordination that emerged from the interviews could be categorized into 3 levels: organizational/system, interpersonal, and individual. In addition, within these levels, we frequently found that the same factors emerged as both barriers and facilitators, including the functionality of clinical information technology systems and the availability of community resources at the organization/system level; interactions with clinicians, patients, and other health care facilities at the interpersonal level; and self-care practices for mental health and wellness at the individual level. We describe these below and include additional supporting quotations for each theme in Table 3.

*Organizational/System Level*

**Workload and Scope of Work.** Several coordinators managed ≥300 patients, and many found their caseload challenging, especially when dealing with time-consuming patients, such as those struggling with mental illness, end-of-life planning, social support, health care coverage, homelessness, and behavioral health aspects of chronic illness. Coordinator 5 emphasized this problem: “There are more patients than you have time to outreach [*sic*] and follow up with to build bonds. . . . Reaching out to every patient every time sounds great but is not realistic if we look at the patient/care coordinator ratio; it is too diluted and a set up for failure.” In addition, colocated coordinators reported being asked to do other tasks (eg, rooming patients, answering phones, processing referrals), further adding to their workload. As coordinator 11 expressed, “I get frustrated when I cannot dedicate more time to the job I was hired for.”

**Table 2. Care Coordinators' Job Functions and Activities**

Job Functions	Coordinator Activities
Identify patients in need of coordination	<ul style="list-style-type: none"> <li>•Review high-risk lists</li> <li>•Conduct chart reviews</li> <li>•Assess patients and determine coordination needs</li> </ul>
Outreach to patients by telephone or mail	<ul style="list-style-type: none"> <li>•Track patients through transitions               <ul style="list-style-type: none"> <li>•Follow-up after hospital or ED discharge</li> <li>•Schedule appointments</li> <li>•Follow up after specialist visits</li> <li>•Reconcile medications</li> </ul> </li> <li>•Contact patients who are overdue for preventive or disease-specific screenings</li> <li>•Facilitate self-care management               <ul style="list-style-type: none"> <li>•Assist with goal setting, disease monitoring, medication adherence</li> </ul> </li> </ul>
Conduct face-to-face patient encounters	<ul style="list-style-type: none"> <li>•Conduct one-on-one office visits               <ul style="list-style-type: none"> <li>•Provide patient education/motivational interviewing on chronic disease, weight management, smoking cessation</li> </ul> </li> <li>•Accompany patients during physician visits               <ul style="list-style-type: none"> <li>•Serve as patient advocate and health literacy interpreter</li> <li>•Reinforce information and instructions</li> </ul> </li> <li>•Visit patients in hospital               <ul style="list-style-type: none"> <li>•Introduce self to facilitate follow-up after discharge</li> </ul> </li> <li>•Make home visits               <ul style="list-style-type: none"> <li>•Assess lifestyle, home environment, family composition, medication adherence</li> </ul> </li> </ul>
Provide social support for patients	<ul style="list-style-type: none"> <li>•Link patients/families with community resources               <ul style="list-style-type: none"> <li>•Research and network with private and public agencies</li> <li>•Help arrange housing, fuel, food, transportation, low-cost medications, dental care, crisis intervention</li> </ul> </li> <li>•Provide emotional support               <ul style="list-style-type: none"> <li>•Serve as a “sounding board,” “listen and validate their experiences,” give praise and small rewards</li> </ul> </li> </ul>
Collect, manage, and exchange data	<ul style="list-style-type: none"> <li>•Conduct extensive chart reviews and update charts</li> <li>•Establish methods of communication between hospital/specialists and primary care practice</li> <li>•Manage preventive screening, chronic disease, high-risk patient registries, transition of care logs, and provider panels</li> <li>•Share outcomes data with practice members</li> <li>•Report data to funding agencies</li> </ul>
Support physicians	<ul style="list-style-type: none"> <li>•Conduct previsit planning               <ul style="list-style-type: none"> <li>•Participate in huddles</li> <li>•Identify patients who are overdue for preventive screenings or disease-specific testing</li> <li>•Anticipate needs of office visit                   <ul style="list-style-type: none"> <li>Obtain records from hospital or specialists</li> <li>Download results from glucometer</li> <li>Give patients depression screening tools</li> <li>Change length of appointments</li> </ul> </li> </ul> </li> <li>•Provide reminders to physicians on gaps in care</li> <li>•Develop and implement care plans</li> <li>•Complete advance directives</li> <li>•Develop agenda and case review sessions for faculty/staff meetings</li> </ul>
Back up clinical and administrative staff	<ul style="list-style-type: none"> <li>•Perform nursing duties               <ul style="list-style-type: none"> <li>•Answer triage calls</li> <li>•Conduct wound care, blood pressure checks, obstetric intakes; give immunizations/intravenous fluids</li> </ul> </li> <li>•Assist with insurance issues and authorizations</li> </ul>

ED, emergency department.

**Table 3. Barriers and Facilitators to Care Coordinators' Work—Sample Quotations**

Themes	Barriers/Facilitators	Sample Comments from Participants
Organization/system level		
Clinical information technology	Barrier: Lack of needed functionality	"I get frustrated with our data collection program because it is quite limited as to the data I can get. Sometimes I have to run multiple reports then combine them to get the patients I need to track—such as multiple chronic condition patients." (Coordinator 11)
	Facilitator: Establishing alternate communication methods	"I have built relationships with staff members in medical records at one of our most utilized hospitals, as well as staff members at other physician offices that we work with most often. Early on, I called them and explained who I was and what my role was. I told them what information I would be looking for and why. We have come up with a fax system. This saves me the time that it would take to be on the phone constantly." (Coordinator 4)
Community resources	Barrier: Challenges identifying community resources	"This has been one of those areas that we have put on the back burner over and over. . . . We have a spreadsheet in a shared file so we can all add new or revised info about what's available in the community. Keeping the data current is an ongoing challenge." (Coordinator 7)
	Facilitator: Strategies for identifying key resources	"Our county has a 'resource jam' twice a year. . . . It is a daylong event, local agencies sign up for 15 minute blocks of time and get a table to put out information on. . . . Fabulous networking goes on. . . . [In addition,] our local Community Service Consortium puts together a guide to community services, which I hand out to patients." (Coordinator 11)
	Facilitator: On-site patient resources	"We are extremely fortunate to have a Clinical Psychologist and a Social Worker on sight [ <i>sic</i> ]. This has been extremely helpful as they are often called to step into an appointment when the patient is being seen. We also now have a PharmD a couple days a week to review patient medications with them too." (Coordinator 21)
Interpersonal level		
Interactions with clinicians and other health care facilities	Barrier: Clinician resistance	"At my present position each provider has so few of my patients and we don't work together on a daily basis. It's difficult I think for them to trust me. . . . Some of them look at it as another intruder telling them what to do with 'their' patients." (Coordinator 17)
	Facilitator: Strong relationships with clinicians	"I have an excellent relationship with the physicians in my office. Not only have I worked with these physicians for nearly 3 years now, but I think the biggest factor is trust. They trust me and my work and my efforts with their patients. They know that I will follow through and keep them informed. Some physicians did give me resistance for quite some time. However, as they began to see the positive results of my efforts, their attitudes changed greatly." (Coordinator 4)
	Barrier: Resistance from other health care facilities	"I have to admit that being able to communicate with inpatient, home health, hospice and therapists is the one area which still remains terribly undeveloped with our practice. Now that we have electronic medical records, I am able to see the inpatient notes better, but after 3 years of trying, the inpatient/ED [emergency department] social workers and care managers still remain ignorant of my existence. I have been successful on a few occasions when I haunted the hospital halls for the nurse/social worker managing my patient while admitted; but I have to really sell my role to get much interaction." (Coordinator 15)
	Facilitator: Strong relationships with staff at outside organizations	"I think we are very fortunate to have great relationships with the hospital staff. We work closely with the care coordinators and the social workers/discharge planners as well. . . . We collaborate with the tertiary care site an hour away for a great deal of the specialty care we can't provide here. They are terrific at sharing! We are working on build [ <i>sic</i> ] stronger community alliances to support our patients with behavioral health needs as well. Our goal is to truly have a community based practice!" (Coordinator 7)

*Continued*

**Table 3. Continued**

Themes	Barriers/Facilitators	Sample Comments from Participants
Interactions with patients	Barrier: Patient resistance; lack of trust	“One major challenge is getting patients to ‘engage’ in care management. Our patients have been assigned to nurse care management due to their pattern of health care utilization. Some of these patients are resistant to talking with a nurse care manager and decline to participate.” (Coordinator 18)
	Facilitator: Developing trust	“One patient after receiving my letter called the office and just wanted to tell the receptionist to give me the message that she did not want any part of my program. The receptionist convinced the patient that she should talk to me directly. After I allowed the patient to vent and ask her questions, by the end of the conversation she said ‘well, you don’t sound too bad. I guess you can come to my house.’” (Coordinator 17)
	Facilitator: Listening to patients	“Another thing I have found is that many people just need someone to listen to them and validate their experience. When they’ve had the chance to talk about their emotions, fears, daily challenges, etc. and someone has truly listened—rather than referring them to yet another person—they often come up with solutions on their own (ie, family, friends, neighbors or community resources they know about, that might help).” (Coordinator 18)
Individual level Self-care practices	Barrier: Lack of attention to self-care	“Just over a year ago I changed jobs because I no longer felt I was taking care of myself—physically, spiritually and emotionally—and it was negatively affecting how I interacted with those I worked with and the patients I encountered—it was scary but necessary and my new position helps me keep the balance.” (Coordinator 3)
	Facilitator: Self-care practices	“There are two things that have been very helpful for me in managing the stresses of so many patients, so little time. They are both things I do for me on the assumption that if I am healthy and serene, I can be more available for those who are not. I take a yoga class right here on the campus once a week. It has been a powerful avenue to increased strength, balance and inner calm. The second is a simple daily practice of staying positive. I start every morning with gratitude for three specific things from the previous day, one thing I am proud of and one thing I am looking forward to . . . it has really reframed the conversation of the day to one that is positive and upbeat.” (Coordinator 7)

Adding to their work burden, coordinators described having 2 competing aspects of their role: data management and case management. Many coordinators were responsible for tracking and entering quality metrics into electronic medical records in addition to helping patients manage their chronic illnesses. Coordinator 3 was optimistic: “I expect the role will transition or there will be 2 separate roles—population management and clinic based case management.” Many felt pressure from leadership to provide to administrators or funders of pilot projects data demonstrating the value of their work. For example, coordinator 18 told us that she “constantly” hears from her “managers and project leader that the ‘higher ups’ in our hospital system want to see the numbers that prove what we are doing is making a difference.” Many coordinators expressed frustration with how poorly these numeric data reflect their merit, explaining how difficult it is “when decision-makers do not

have the ability to hear patient voices directly and resources (funding) is [*sic*] based solely on numbers” (coordinator 19).

**Functionality of Clinical Information Technology.**

The data management aspect of care coordination is made more challenging by information technology systems that lack necessary functionality. For example, care coordinators reported working with electronic health records (EHRs) that are incapable of running reports on specific patient populations—an essential feature for managing patients with chronic conditions. Coordinators reported devising workarounds, such as running “multiple reports, then combin[ing] them to get the patients I need to track” (coordinator 11). In addition, coordinators responsible for a subset of the patient panel reported lacking efficient ways to identify their patients in the practice schedule. One participant wished for “a daily report that tells me which

of my patients were coming in that day instead of having to open 100+ charts daily to look for them” (coordinator 23).

Lack of interoperability with specialists and hospital information technology systems was also a barrier, but some devised solutions through building relationships with staff members at other facilities and relying on other forms of communication, such as facsimile. Others described important efficiencies created by EHR software capable of sharing patient information with outside organizations: “We now have Epic and have recently been able to electronically request outside records, if they are on Epic too, and can instantly get those in the patient electronic chart. It is amazing and makes me almost giddy, especially collecting some of that outside lab information” (coordinator 20).

**Availability of Community Resources.** Finding community resources for patients was an ongoing challenge for many care coordinators. Necessities included transportation to appointments, affordable medications and supplies, diabetes management and smoking cessation programs, low-cost dental care, and behavioral health, mental health, and psychiatric medication support. Some emphasized the limited availability of resources in their communities as a serious problem: “It is difficult to get patients ‘plugged in’ to resources when there is not much to offer” (coordinator 19). Others feared they might not be aware of all available resources. Consequently, a common item on care coordinators’ wish lists was a local “resource directory.” Several coordinators reported trying to create such a directory, but “keeping the data current” was a major obstacle. Care coordinators working in offices with on-site mental health and other resources for patients characterized this as a major facilitator, as these resources could be integrated into a visit. Others were fortunate to have community agencies disseminate information and guides about community services. For care coordinators without on-site resources, having systems in place to gather information about social agencies was very helpful.

#### *Interpersonal Level*

**Interactions with Clinicians and Other Health Care Facilities.** Care coordinators emphasized that good working relationships with clinicians facilitated their work. For example, colocated coordinators reported the value of participating in team

huddles and staff meetings for facilitating information sharing and their integration into the practice, whereas coordinators located offsite reported that reduced face-to-face contact constrained their ability to develop relationships and communicate effectively. Coordinator 18 explained, “When patients have requests or concerns, I frequently cannot ask their provider in person. I have to send them a message through the EHR. It slows things down and creates lots of opportunities for miscommunication.”

Regardless of location, coordinators consistently stressed the importance of “winning over” the physicians in their offices. Many felt that clinicians often initially viewed them as “trying to get between me and my patients” or as adding to their workload: “It is so hard to get them (physicians) to understand that our goal is to be a team member, to support them and advocate for their patients and help their patients be healthier. MDs are often the biggest barrier in the coordination process” (coordinator 3). Coordinator 18 commented: “My former career, before nursing, was in marketing. I am surprised by how much I use those communication (almost ‘sales’) skills to promote myself as a resource.” Some expressed discomfort with “selling” themselves to clinicians.

Relationships with clinic team members are critically important for care coordinators, but also important are the relationships that they develop with people outside of the practice who may be caring for their patients. Coordinators described “meet-[ing] a ton of resistance” when trying to acquire information on mutual patients from other health care facilities (ie, hospitals, nursing facilities, specialists’ offices). By contrast, those coordinators with good working relationships with external health care facilities found them invaluable. Notable were descriptions of personnel in local hospitals who reliably provided timely hospital and emergency department discharge information.

**Interactions with Patients.** Coordinators reported that interactions with patients could be a barrier to care coordination because of patients’ lack of trust, insufficient understanding of the care coordinator’s role, and inability to take responsibility for self-management of chronic conditions. Coordinator 18 described how some patients who agree to work with her continue to call multiple people in the clinic instead of her, and they con-



tinue to go to the emergency department for needs that would best be treated in the clinic. Consequently, these patients “technically have a nurse care manager but they continue to have fragmented care.”

To help engage patients, several coordinators reported using strategies like motivational interviewing (MI).<sup>36</sup> Coordinator 24 explained that this technique has been so effective that she has begun teaching it to the clinicians. Similarly, in coordinator 19’s practice, the whole care team meets monthly for an “MI club” to practice role-playing with “difficult patient” scenarios. In addition to MI, other strategies care coordinators used to engage patients included being patient but persistent, keeping promises, listening carefully, using humor, sharing personal anecdotes, and earning trust with small gestures so larger problems could be tackled later.

#### *Individual Level*

A few coordinators experienced difficulty managing the stresses of the position, particularly the emotional labor of getting both patients and other providers to “buy in” and the demanding workload. Some coordinators also struggled with maintaining appropriate emotional boundaries with patients. Many participants emphasized the importance of attending to self-care—both mental and physical—to optimize their ability to work with patients. Self-care practices varied, including yoga, mindfulness/meditation, seminars, books, workshops, and personal rituals that promote positivity and gratitude. In addition, having a forum for social networking and support can alleviate stress. “One of the most beneficial aspects of this experience [participating in the discussion forum],” coordinator 19 explained, “has been the ability to hear other stories and perspectives, the good and the more challenging. It has helped me to know that many of my daily struggles are experienced by several of us and that I am not ‘alone.’ That sense of community has been invaluable.”

## **Discussion**

### ***Study Contribution***

This is the first study describing experiences of care coordinators across the United States from

their own perspectives. The prospective online discussion forum enabled us to hear from care coordinators directly and involve them in the analysis. In addition, our findings overlap meaningfully with more general research (not specifically from the care coordinator’s perspective) on barriers and facilitators to the initial implementation of this new role,<sup>8,37,38</sup> particularly the barriers of inadequate technological support, financing problems, insufficient staffing, practice buy-in, and the challenge of measuring success in care coordination.

A prominent cross-cutting theme from our data is the importance of developing relationships for effective care coordination, an idea also stressed in prior research on care management and practice improvement.<sup>39,40</sup> Most of the barriers and facilitators identified relate directly to relationship building. For example, the barriers of insufficient technology or physician and patient resistance limit care coordinators’ ability to cultivate the necessary relationships for effective communication. Similarly, the facilitators described enhanced communication with both patients and clinicians, for example, having on-site mental health services, EHRs that interface well with outside organizations, or training in MI.

### ***Limitations***

While our findings are based solely on care coordinators’ perceptions, the richness of our real-time forum data provides in-depth insight into what care coordinators experience on a day-to-day basis. A limitation of using an online discussion forum, rather than traditional focus groups or interviews, was the requirement that participants feel comfortable using the Internet and navigating our website, which may have introduced a sampling bias. We believe this bias is small, since a growing number of people regularly use computers or smartphones for online social networking.<sup>41</sup> Another limitation of our research design is that it did not allow us to systematically count or track themes. With the exception of the initial “grand tour” question, we did not require every participant to answer every question; we posted questions and allowed respondents to respond as they wished. Finally, individuals who had strong opinions about their role may have been more likely to volunteer for this study and post lengthier responses.

### **Implications for Practice**

Based on these findings, we identified 4 key areas to address with practice and system changes. First, strategies are needed to effectively integrate care coordinators into patients' health care teams and to minimize providers' resistance. Potential strategies include embedding care coordinators within a practice to help with relationship building<sup>24</sup> and scheduling team meetings where care coordination success stories and improved clinical outcomes are shared.<sup>42</sup>

Second, to maximize their effectiveness, care coordinators need enhanced resources and improved infrastructure to better coordinate and manage complex cases, for example, accessible mental health and social work services, or a readily available directory of resources for patients. More research is needed on the best ways for care coordinators to learn about and develop linkages to community resources. Programs such as *HealthRx*, where students walk each block in South Chicago to map and catalog all community organizations,<sup>43</sup> is one potential strategy.

Third, it is necessary to better define the optimal job activities and caseload for care coordinators in primary care. Based on our findings, having the same person doing both data management and casework is unmanageable. Reassigning tasks that can be accomplished by lesser-trained staff would help to decrease coordinators' caseloads so they can work at the top of their license.<sup>44</sup> Our research also suggests that it would be beneficial to establish additional ways to evaluate and pay for care coordinators' work. Many respondents expressed frustration that current evaluation methods, typically using quantitative data, cannot capture the actual contributions of their work with patients.

Finally, given the challenges of their role, particularly their work with resistant and complex patients, it is necessary to find ways to provide more mental health and wellness support for care coordinators themselves. Educating coordinators to set boundaries with patients and allotting time for self-care may help them avoid burnout.<sup>45</sup> In addition, creating a formal network and support system for social interaction and collaborative learning—for example, via an online discussion forum or other social networking venue—can serve as a valuable resource.

### **Future Research**

As the new role of care coordinator is increasingly implemented in primary care practices nationwide, more research is needed to comprehensively study care coordinators' perspectives alongside the viewpoints of clinicians, other staff, and patients so that their activities and caseloads can be optimized. For example, future studies might elucidate the ideal activities and patient population to target for care coordinators to help achieve the triple aim of health care reform efforts (improving patient experience of care, improving population health, reducing the cost of care).<sup>15,46</sup> These multiple viewpoints would also help to clarify the optimal training and background needed, especially in the use of information technology, communication techniques, and patient engagement strategies. In addition, these multiple perspectives would be beneficial for strategizing the best way to implement and integrate the care coordinator role into the patient care team and office workflow, such as when in-person interaction with patients and health care providers might be preferred over more efficient computer- or telephone-based interactions. Finally, future studies including a larger and more diverse sample of care coordinators are needed to better understand facilitators and barriers in developing relationships with health care providers, maintaining boundaries with patients, and in dealing with potential burnout.

### **Conclusion**

Our research indicates that the following factors can either impede or facilitate the work of care coordination: functionality of clinical information technology, particularly interoperability with outside organizations; access to resources for patients; degree of integration within a practice; interactions with clinicians, patients, and other health care facilities; and self-care practices. All of these areas were identified in our research as both barriers and facilitators to effectively coordinating care, suggesting that these are likely productive areas to target education and practice change efforts. While all the barriers and facilitators were important to performing their role, relationship building stood out as key to effective care coordination, whether with clinicians, patients, or outside organizations.

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## Appendix

### *Areas of Focus for Interviews Based on the Organizational Design Framework*

#### I. Grand tour questions

1. What is your job title and description? Please describe a typical workday for you.
2. When was your position created? Tell us what you know about how and why it came to exist and how it was implemented.

#### II. Baseline assessment of coordination needs

1. Identification and assessment of patients in need for coordination services
  - a. How do you identify patients in need of coordination?
  - b. How do you decide which patient population to focus on (eg, is it based on demographics, complexity of diseases, uncertainty of patient compliance, use of medical care in multiple settings)?
2. Role identification in care coordination
  - a. How do you identify providers involved in the patients’ care planning?
  - b. What are some strategies you use to identify community resources?
  - c. Tell us about times when you have relied on other people to gather information about your patients.

#### III. Coordination mechanisms

1. Grouping
  - a. How are you integrated with other practice members and within other practice-wide care processes?
2. Operational processes of care coordination:
  - a. How is information communicated between providers and between patient/family and providers?
  - b. What kind of external requirements from pilot projects/funders influence your work?
  - c. Could you tell us about a success story you have had coordinating care?
  - d. Tell us a story about a challenge you have faced or a frustration you have encountered while coordinating care.
3. Structural linking
  - a. What tools, resources, and mechanisms (eg, information systems, team meetings) enhance information exchange?
  - b. What relationships need to be developed for your job to be successful?