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Patient, PCP, and specialist perspectives on specialty care coordination in an integrated health care system

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Abstract

Successful coordination of specialty care requires understanding the perspectives of patients, PCPs, and specialists - i.e. the specialty care "triad". This study used qualitative methods to compare these perspectives in an integrated healthcare system, using diabetes specialty care as an exemplar. PCPs and endocrinologists relied on inter-clinician relationships to coordinate care. Clinicians rarely included patients or other staff in their conceptualization of specialty care coordination. Patients often assumed responsibility for specialty care coordination but struggled to succeed. We identified several opportunities to improve coordination across the triad. In an integrated medical system, the shared organizational structure can facilitate these efforts.

Keywords

care coordination;	specialty care; r	eferrals; qualita	ative methods	

INTRODUCTION

Specialty care is an increasingly important element of outpatient care. From 1999–2009, referrals in the United States more than doubled from 41 million to 105 million.(Barnett, Song, & Landon, 2012) Increased referrals result in increased health care fragmentation across providers, which is in turn associated with missed and unmet needs(Committee on

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Quality Health Care in America, 2001), duplicated tests(Parchman, Noel, & Lee, 2005; Stille, Jerant, Bell, Meltzer, & Elmore, 2005), medication errors(Fialova & Onder, 2009), and patient confusion(Anderson, Barbara, & Feldman, 2007). Risks increase exponentially with more sources of medical care(Schoen, Osborn, How, Doty, & Peugh, 2009), putting sicker patients at greatest risk and increasing costs(Committee on Quality Health Care in America, 2001). Specialty care referrals therefore present a serious challenge to successful achievement of high-quality, high-value, patient-centered care through patient-centered medical homes (PCMHs) and accountable care organizations (ACOs).

Care coordination is the deliberate organization of patient care between two or more participants (including the patient) to account for each other's actions and facilitate the appropriate delivery of healthcare services. (McDonald et al., 2010) Coordination to prevent fragmentation is a cornerstone of the PCMH and a *sine qua non* of the ACO. The primary care provider (PCP) is often charged with responsibility for coordinating care, but successful coordination is actually contingent upon the sharing of information and treatment plans among all three members of a specialty care "triad" – patient, PCP, and specialist. Ensuring successful specialty care coordination within new models of care, therefore, depends on understanding how each triad member experiences specialty care coordination and how each addresses coordination challenges.

Whereas prior literature focuses on either clinicians alone or patients alone (Forrest et al., 2000; Hysong et al., 2011; Mehrotra, Forrest, & Lin, 2011; O'Malley & Cunningham, 2009; O'Malley & Reschovsky, 2011; Physicians, 2010; Stille, Primack, McLaughlin, & Wasserman, 2007; Wasson, 2008; Wrobel et al., 2003; Yee, 2011; Zuchowski et al., 2015), we examine the experiences of all three triad members to develop a more comprehensive understanding of specialty care coordination and how it may be improved. Using diabetes specialty care as an exemplar, we conducted a qualitative study in the Veterans Health Administration (VHA) with patients, PCPs, and endocrinologists to examine the factors determining success in specialty care coordination from the perspective of each and identify opportunities to improve coordination for each. VHA is the nation's largest integrated health system, serving over 6 million patients annually. Lessons learned from this very large system may offer ideas for optimizing specialty care coordination in newer integrated systems such as ACOs.

METHODS

Participants

We conducted interviews and focus groups with Veteran patients with diabetes, VHA PCPs, and VHA endocrinologists. We recruited clinicians across the country through email from a purposive sample of VHA medical centers (PCPs and endocrinologists) and community-based outpatient clinics (PCPs only) to maximize variation in practice by facility region, size, and rurality.

Patients were recruited from one urban and one rural VAMC within VA New England Healthcare System (VANEHS). We did not interview triads linked by a single encounter because of the difficulty of scheduling interviews with 3 people linked by a single visit.

Patients were eligible who in the last 9 months had (1) at least one PCP visit and (2) at least one endocrinologist visit with a primary diagnosis of diabetes (ICD-9 code 250.XX). An invitation and "opt out" card was mailed to 120 eligible patients from each site. Those not opting out were contacted by telephone, screened, and invited to participate. We stopped contacting patients when 16 participants agreed to join a focus group (8 per VAMC). Following focus group completion we enrolled additional patients for individual telephone interviews, until data analysis indicated that we had reached "thematic saturation", the point when no new concepts are discovered in the data.(Safman & Sobal, 2004). We excluded those with limited English proficiency or cognitive impairment as determined by ICD-9 code.

The Bedford VA Medical Center Institutional Review Board approved this study. All participants provided informed consent.

Data collection

Interviews and focus groups were conducted between April–October 2014 using semi-structured guides (Supplemental Digital Content). Clinicians were interviewed by telephone. Patients participated in one of two focus groups or by telephone. Interviews and focus groups were conducted by the lead investigator (VV) and/or BB.

Participants were asked to describe experiences with well- and poorly-coordinated specialty care for diabetes. We asked about what was required to coordinate, who and what were involved, and how participants communicated with and determined each other's roles and responsibilities. We also queried about perceived barriers and facilitators to coordination. Patients received a \$45 gift card. Interviews and focus groups were audio-recorded and transcribed verbatim.

Data analysis

Transcripts were reviewed for accuracy and analyzed using thematic analysis informed by grounded theory, which provides a systematic approach to deriving themes from textual data. Three investigators (VV, KD and BB) analyzed 10 transcripts together to establish consistency in coding and develop a codebook. Each investigator used the codebook to code subsequent transcripts.

We began with a set of a priori codes informed by the extensive literature on care coordination. (J.H. Gittell, 2000; McDonald et al., 2010) We included concepts that have been linked to clinical outcomes. These included Interpersonal Communication, Continuity, Data Transfer, Relationships, and Roles and Responsibilities. (Daley et al., 1997; J. H. Gittell et al., 2000; J. H. Gittell, Weinberg, Pfefferle, & Bishop, 2008; Havens, Vasey, Gittell, & Lin, 2010; Shortell et al., 1994; Weinberg, Gittell, Lusenhop, Kautz, & Wright, 2007; Wrobel et al., 2003; Young et al., 1997; Young et al., 1998; Zimmerman et al., 1993) We used thematic analysis to identify new codes grounded in the data. The team elaborated, split or combined new and a priori codes using the constant comparative method.(Strauss, 1987) For each triad member type we conducted interviews until we reached thematic saturation.(Safman & Sobal, 2004)

We compared themes across triad members to identify areas of concordance and discordance in the understanding of what is most important for successful specialty diabetes care coordination. The entire research team reviewed the themes for relevance to the concept of successful specialty care coordination. We selected exemplary quotes based on their relevance and clarity of expression. Data analysis was facilitated using NVIVO, a qualitative data management software package.("NUD*IST VIVO (NVIVO)," 1999)

RESULTS

Overview

We conducted two 60-minute focus groups with 9 patients (N=4 and N=5) and interviewed an additional four patients by telephone. We interviewed 12 endocrinologists. From primary care, we interviewed 10 MDs, 1 NP and 2 RNs. We interviewed RNs to explore whether their perspectives of successful specialty care coordination were very different from PCPs, but they were not and so we grouped them with PCPs in our analysis. Interviews ranged from 16–45 minutes. Participant characteristics are in Tables 1 and 2. Clinicians represented 23 different VHA facilities in 10 different VISNs. Six patients were from the rural VAMC and 7 were from the urban VAMC in VANEHS.

We identified four overarching themes common to PCPs and endocrinologists and two overarching themes among patients with respect to what was most important to successful specialty diabetes care coordination. Within these overarching themes, triad members valued similar aspects of coordination – interpersonal communication and data transfer that are clear, detailed, accurate and timely; relationships with each other that are positive and respectful; roles and responsibilities that are clear and mutually acceptable; and an organizational context that supports achievement of these qualities. There were, however, important differences across triad members. PCPs and specialists were more similar in their perspectives on coordination than either one was to patients. In what follows, therefore, we organize the themes into: 1) PCP and endocrinologist perspectives; and 2) patient perspectives. Exemplary quotes are in Table 3.

PCP and endocrinologist perspectives

Clarity and agreement on clinician roles and responsibilities are fundamental

—Both PCPs and endocrinologists emphasized the need for clarity regarding respective roles and responsibilities but often disagreed about what each other's responsibilities were. For example, many PCPs felt specialists should provide care between specialist clinic visits, while several endocrinologists lacked resources for interim care and deferred this role to the primary care team. PCPs and endocrinologists described frequent disagreement about what constituted a sufficient PCP workup prior to referral. Ongoing disagreement about roles and responsibilities complicated patient care and frustrated clinicians.

Some endocrinology clinics provided care coordination agreements outlining each clinician's referral responsibilities, but documents developed by the specialty service unilaterally were often poorly received by PCPs. One PCP described how endocrinologists and PCPs at his facility collaboratively developed their coordination agreement. He reported

satisfaction, clarity and agreement with his and the endocrinologists' roles in diabetes referrals.

Limitations to coordination through the shared electronic medical record—

Both clinician types described the importance of clarity and detail in EMR-based communication. Endocrinologists wanted referral requests that summarized relevant background information, workup or treatment to date, and expectations for the consultant's role; these data improved efficiency of the consultation. PCPs described how consultants' notes should demonstrate thorough consideration of the clinical question and guide subsequent clinician roles and responsibilities.

Even when clinicians wrote clear and detailed notes, however, the EMR was insufficient to convey the clinical complexity and urgency needed to coordinate care. In addition, when responsibility for follow-up was ambiguous, data could be entered in the EMR but never acted upon.

Overall, despite the ubiquitous and necessary use of the EMR, PCPs and specialists reported that its ineffective use and inherent limitations frequently resulted in poor coordination. This included unclear follow up plans, confusion about roles and responsibilities, missed opportunities for care, duplicated tests and services, and wasted time and effort.

Direct communication and strong clinician relationships help overcome EMR limitations—Several PCPs and endocrinologists described how direct, synchronous communication was critical to overcome the limitations of the EMR for coordination. Direct communication allowed clinicians to convey concerns, clarify uncertainty, and expedite patient care. Yet organizational barriers to direct communication were formidable, including scant opportunities for chance face-to-face encounters, the absence of a clinician directory, and part-time specialists who rarely used VHA communication tools.

Both PCPs and endocrinologists emphasized that, in the face of such barriers, success in communication often hinged on pre-existing collegial relationships with each other. Interclinician relationships had a direct impact on timeliness of care and on resource utilization. Those who "knew people" were able to easily reach others to coordinate care. Those who did not have personal contacts compensated in different ways. Some PCPs who could not reach endocrinologists for straightforward "curbside" questions would just place a referral; others were less likely to refer patients to services they perceived as non-responsive.

Patients and other health care team members are seen as having a limited role in specialty care coordination—Most clinicians did not spontaneously mention the role of patients in coordination. When asked, clinicians usually described the patient role as limited to keeping appointments and bringing their glucometers in order to review blood glucose data gathered at home. A few clinicians felt that patients should function as backups to busy physicians. These clinicians felt that although it was their own responsibility to facilitate many processes, there were simply too many moving pieces. Therefore, they depended on patients to ensure that different aspects of care were coordinated and completed.

Other healthcare team members were rarely mentioned in the context of coordinated specialty care. PCPs did rely on nurses and pharmacists to provide diabetes care, but neither PCPs nor specialists discussed their role in coordination.

Patient perspective

Specialty care coordination occurs at multiple levels—In contrast to clinicians, patients described successful coordination of diabetes care as a combined effect of organizational function, their interactions with various health care providers and non-clinical staff, and their own personal effort.

Good clinic organization was considered a sign of well-coordinated care. Examples included timely appointment starts, provider continuity, and return appointments booked at the end of the visit. Patients appreciated receiving care in the most efficient mode appropriate to the situation, whether by video, telephone, secure messaging or face-to-face. Poor coordination included clinical redundancy and excessive travel due to appointments scheduled with multiple types of providers for diabetes care.

Among healthcare providers, patients often identified non-physicians, such as primary care nurses, telehealth nurses, and clinical pharmacists, as the greatest help in ensuring that health care delivery was coordinated across clinicians. Patients described PCPs and endocrinologists as responsible for good documentation, reading each other's notes, conveying a clear follow-up plan to the patient, responding to patient communication, and reporting on test results in a timely manner.

Who is primarily responsible for coordination of specialty care?—Patients differed in the perception of who had primary responsibility for coordination. Patients who felt that coordination was their responsibility took on that role because they worried that others in the healthcare system would or could not. These patients described their role as keeping track of and attending appointments, maintaining medication logs, and carrying copies of their own clinical notes to different clinicians within and outside VHA. Taking an active role in coordination helped patients compensate for an imperfect system to avoid redundant appointments, missed test results, and obtain appropriate attention when needed.

Other patients felt that it was vital to have a relationship with one specific person from primary care who could coordinate their specialty care. The most helpful contact was usually a non-physician clinical staff member, e.g. a nurse or clinical pharmacist. Several patients commented on how these individuals were easy to contact, arranged appointments and tests, facilitated communication with clinicians, and noticed when things were amiss. Those who needed but did not have a trusted point of contact were frustrated and felt they were "falling through the cracks".

CONCLUSIONS

Coordination of specialty care is a critical function of contemporary health care delivery systems. The goal of our study was to elucidate the perspectives of the specialty care "triad" - patients, PCPs and endocrinologists - to identify potential opportunities for improvement.

Our work extends prior literature focused on the coordination process from the perspective of only one or two triad members. (Hysong et al., 2011; Mehrotra et al., 2011; Zuchowski et al., 2015) By examining the triad, we identify opportunities for better coordination not only between PCP-patient or specialist-PCP, but across all three direct participants in specialty care.

Clinicians required excellent coordination with each other, but clinicians' work suffered from a lack of procedures and protocols to clarify roles and responsibilities related to the organization of specialty care, i.e. "programming approaches" in organizational theory. (Charns & Young, 2010) We also identified a lack of opportunities for PCPs and endocrinologists to communicate directly, which could have helped compensate in real-time for the lack of pre-existing role clarity and limitations to the EMR for coordination. Organizational theory stresses the importance of this "feedback approach" as a complement to programming approaches when work is highly complex and interdependent. (Charns & Young, 2010)

Care coordination agreements are a promising programming approach to address the need for clarity and agreement on clinicians' roles during the referral process.(Carrier, Dowling, & Pham, 2012; Physicians, 2010) It is unknown whether broad multidisciplinary agreements(Greenberg, Barnett, Spinks, Dudley, & Frolkis, 2014) would be more effective than specialty-specific agreements in large integrated systems, and how such agreements would be enforced. To ensure buy-in of any such agreement, both PCP and specialist stakeholders must be involved in the development process. In our study, this was not the default approach.

Greater EMR flexibility is needed, but EMRs alone are insufficient for time-sensitive or complex inter-clinician communication. (Hysong et al., 2011; Zuchowski et al., 2015) To compensate, health care organizations might implement straightforward mechanisms such as call hours and telephone directories. The effectiveness of these would be multiplied by strong inter-clinician relationships. An explicit health system focus on improving personal relationships (Yee, 2011) could include opportunities to interact that are purely social rather than task-based, and identification of clinician relationship-building as a goal of coordination improvement.

In sharp contrast to clinicians' perspectives, patients' views on the key participants in specialty care coordination extended beyond PCP and specialist to include the health care organization, nurses, clinical pharmacists, and patients themselves. We identified two different patient perspectives on coordination across these different levels that reflect the difficulty that the health care system has in keeping track of all the moving parts of care. One perspective correctly identifies the health care facility's responsibility to provide coordinated care, and depends on it to do so; the other perspective results in patients taking matters into their own hands.

Patients in the second group create their own safety net to compensate for failure of the system and their clinicians to achieve reliable coordination. Their ability to do this, however, is limited to keeping track of appointments, medications and medical records. Such efforts

are important, but cannot ensure well-coordinated care because they cannot reach the interclinician interface or adequately overcome shortcomings at the organizational level. Despite their best efforts, patients cannot – and should not be expected to – fully succeed in coordinating their care. By contrasting clinician and patient perspectives, we identify strategies to improve coordination from the patient perspective.

Patients identified a central role for nurses and clinical pharmacists in specialty care coordination, but PCPs and specialists did not recognize this role. In general, specialist communication with non-PCP staff in the PCMH is limited, but there is an apparent opportunity to leverage a resource that patients already rely on. Health care organizations could better define and support the role of PCMH nurses and clinical pharmacists in coordinating specialty care. As in the PCP-specialist dyad, expectations for PCMH staff-to-specialist communications should be formalized but are likely to flow more smoothly if personal relationships are established.

PCPs and specialists often omit patients from their conceptualization of coordination. They therefore miss opportunities to effectively engage patients as decision-makers about, rather than negotiators of, coordination. However, eliciting patients' values, preferences and needs regarding how their care is delivered is central to successful organization of specialty care. (Taylor, Lake, Nysenbaum, Peterson, & Meyers, June 2011) EMR modifications could help clinicians support the patient as decision-maker in coordination, for example through computerized prompts during clinic visits encouraging clinicians to ask patients' preferences about appointment scheduling and communication.

This study compares and contrasts how each member of the specialty care "triad" – patient, PCP, and specialist – experiences coordination challenges in a large integrated medical system. In doing so, we identify several promising targets for improvement. We also identify several practical strategies that could improve specialty care coordination within the organizational constraints of the current system. These include care coordination agreements and templates for structured data developed in a process that includes specialist and PCP input, clinician directories and call hours, provision of opportunities for inter-clinician social interaction, and EMR prompts and templates that improve specialists' ability to assess patients' coordination needs. Given the importance that patients place on non-clinicians in coordinating specialty care, formalized specialist interactions with designated care coordinators in the PCMH may be particularly valuable. In integrated care delivery models, specialists and primary care teams work under the same organizational roof to serve the same set of patients. This structure provides opportunities for VHA and ACOs to improve specialty care coordination by building approaches that serve all three members of the "triad".

Limitations

We focused on diabetes care, but diabetes may serve as an exemplar for specialty care coordination for other chronic medical conditions. Also, we report on the experiences of triad member types within VHA. All of the patients were Veterans and were men. As such we do not know whether these perspectives are generalizable to all patients, PCPs, and endocrinologists. The strength of our findings, however, lies in the intersection and contrast

of themes across the triad. The richness of the qualitative data here thus may form the foundation for a model of care coordination to be examined in future studies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Characteristics of Veteran patient participants

Characteristic	N=13
Age in years (mean, SD)	58 (12)
Male gender	13 (100%)
Highest level of education	
High school completed	0 (0%)
Some education after high school	6 (46%)
Completed education after high school	7 (54%)
Yearly income in dollars	
Less than 20,000	1 (8%)
20,000–49,999	7 (54%)
50,000–74,999	2 (15%)
75,000 or more	3 (21%)
Number of times received VHA care in last 3 months	
1–3	5 (38%)
4–6	5 (38%)
7–9	2 (15%)
More than 9	1 (8%)
Any care received from non-VHA providers in the last 3 months	
Yes	5 (38%)

Table 2

Characteristics of clinician participants

Characteristic	PCPs (N=13)*	Endocrinologists (N=12)	
Male gender	6 (46%)	8 (75%)	
Years in VHA (mean, SD)	10 (6)	14 (10)	
Total years in practice (mean, SD)	13 (6)	19 (8)	

^{*} includes 10 MDs, one NP and two RNs

Table 3

Representative quotations about key aspects of specialty care coordination

PCPs and Endocrinologist Perspectives	
Clarity and agreement on clinician roles and responsibilities are fundamental	"Typically you assume that the person writing the note is responsible for the action item but what we found is that's not consistently the casewe've had no end of trouble with assuming that one side or the other is coordinating a test, study, or patient communication"(PCP 12)
	"Most critical is closed-loop communication between the consulting service and the primary care provider in a consistent and reliable fashion followed with clear expectations around new patients and identifying who owns which piece of chronic care management or diagnostic management. There are too many dropped balls otherwiseIt just creates an imperative to have clear and transparent communication about roles and responsibilities." (Endocrinologist 4)
Limitations to coordination through the shared electronic medical record	"If I have a patient who is complicated there's really no way I can summarize those nuances in a consult request and the patient can't tell the story and there's no way you'll get it from the chart except by looking through years of notes. There's just no way to effectively get the information across in the chart." (PCP 6)
	"I think [it] was intended that the primary care physician would utilize the specialty providers to address [the uploaded blood sugars] but it's never been laid out so explicitly, and what usually happens is nothing. This mass of data bombards the PCPs and few treatment decisions are madeVERY occasionally that information is forwarded to [me] with no inquiry as to whether we recommend any action. There's a transfer of information but there's no coordination." (Endocrinologist 2)
Direct communication and strong clinician relationships help overcome EMR limitations	"If the question's not worth a full consult I'd love to be able to just call real quick, but I don't know who they are or how to reach themit's not knowing physically where they are, not wanting to have to page them and wait for a call back, not being able to pick up a phone and get to them directly." (PCP 1)
	"I know who most of the endocrinologists are. I've worked with them a long time so I'll just call them. Not everybody does that or feels comfortable or even knows who these people are. But I'd rather get it done right now than send a love letter and hope they get back to meand you know, it's hard to be rude to someone that you know, right?" (PCP 11)
Patient Perspectives	
Specialty care coordination occurs at multiple levels	"Coordinated care? That means everything is workingall my medications are arriving, all my questions are being answered, and I'm doing what I'm supposed to do." (Focus Group 1)
	"Tve got a voice that I speak to named [X] and she is absolutely super. She contacts the primary care doctor and my diabetes doctorshe does my prescription order and all that. I take twenty-one pills a daybut I don't even think about itit's like your guardian angel. She's a registered nurse. She knows everything there is to know actually." (Focus Group 2)
Who is primarily responsible for coordination of specialty care?	"They do an excellent job but it's getting to the right person and sometimes there's a delay. But at the same time the ultimate responsibility for my healthcare lies with me" (Focus Group 2)
	"I have obviously got a problem with my diabetes but I have not had a blood test done in six months. I don't have doctor's appointments. I call up to make a diabetes specialist appointment and my appointments are three or four months outI have nobody to call and don't know who can help me. Now I understand that I could be more proactive and I could force the issue but what I don't understand is why do I have to maintain everything about me when it comes to their appointments? How do I even do that?" (Focus Group 1)