Coordinating Care:
A Perilous Journey Through the Health Care System

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Introduction

For 45 years, my uncle was a general practitioner. Except for rare few-day vacations, he was on call 24/7/365 during 45 years. For most of his patients most of the time, care coordination was not needed. He handled everything, including hospitalizations. He occasionally had to coordinate with specialists, hospital nurses, pharmacists, home care agencies, or emergency departments. My uncle was extremely nice and his patients loved him. He retired 12 years ago at the age of 83 and died 2 years ago at the age of 93. On the spectrum of continuity and coordination, he was at the continuity pole.

Professor Famous J. Goode runs an internal medicine department at a well-known medical school. He sees patients in the general medical clinic 1 afternoon a week – that is, when he is not traveling to an important meeting. During 164 out of the week's 168 hours when Dr. Goode is not available, patients needing care see a resident or medical student in the clinic, go to urgent care or the emergency room. Sometimes these other clinicians let Prof. Goode know what happened with his patients; usually they do not. Prof. Goode is extremely nice and his patients love him. On the spectrum of continuity and coordination, he is at the coordination pole.

Continuity of care and coordination of care can be viewed as opposite ends of a spectrum. The traditional conception of continuity of care is the relationship between a single practitioner and patient that extends beyond specific episodes of illness or disease [1]. When continuity is near-total, as with my uncle, coordination is rarely needed. When continuity is limited, as with an academic department chair, coordination is constant and essential.

Care coordination has been defined as "a function that helps ensure that the patient's needs and preferences for health services and information sharing across people, functions, and sites are met over time. Coordination maximizes the value of services delivered to patients by facilitating beneficial, efficient, safe, and high-quality patient experiences and improved healthcare outcomes [2]. Care coordination is often perceived only as interactions among different care providers (provider-provider coordination). However, care coordination should also involve interactions between providers and patients/families (provider-family coordination).

Coordination of care has grown in importance as primary care clinicians increasingly work part-time and as patients kept alive with medical advances become more complex, requiring services from multiple providers. However, a number of primary care practices – small private offices, concierge practices, large integrated medical groups, and community health centers -- with near full-time clinicians strive to offer care closer to the continuity pole [3].

The domains of care coordination

Care coordination takes place in a vast number of domains of care. A partial list of these domains is shown in Table 1.

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Table 1: Domains of care coordination

Provider-provider

Within a primary care practice

PCP* – other clinicians** in the practice
PCP – non-clinician staff in the practice
Other clinicians in the practice – non-clinician staff in the practice
PCP - physician on call nights and weekends

Between a primary care practice and other providers

PCP - specialist
PCP - ancillary (lab, imaging, physical therapy, social worker, etc.)
PCP - pharmacy
PCP - emergency department
PCP - hospitalist
PCP - home care RN
PCP - nursing home
PCP - insurance company
PCP - mental health system

Among other providers

Specialist – hospital
Specialist - hospitalist
Specialist – pharmacy
Specialist – imaging
ED – hospital
ED – pharmacy
ED – imaging
Disease management RN – other providers
Hospital – home care RN
Hospital – pharmacy
Hospital – SNF
Hospital physicians – hospital nurses
Hospital physicians – hospital lab/x-ray
Hospital nurses AM shift – hospital nurses PM shift

Provider-family

PCP - patient
PCP – family
Family caregiver - patient
Other primary care clinicians/staff - patient/family
Specialist - patient/family

Disease management RN – patient/family
Pharmacy - patient/family

*PCP = primary care provider
**Clinician = physician, nurse practitioner or physician assistant

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Risk factors for needing provider-provider care coordination

A few patients never need provider to provider care coordination. They are healthy people with a PCP whom they can see whenever they have a health care need and who never require an emergency department visit. But the majority of the 300 million people in the US are likely to need provider-provider care coordination at some point in time. At greatest risk of needing care coordination are the 125 million people with chronic illness, disability or functional limitation [4]. 2 major factors increase the risk of needing care coordination: many doctors and many illnesses – factors that usually go together.

Approximately 5% of primary care visits result in a specialty referral, 71% involve a prescription, 36% a laboratory test, and 13% an imaging study; all these situations require care coordination [5]. In 1996, 3.4% of patients without a chronic condition or functional limitation were hospitalized, none needed home care visits, and the average patient had 1.7 physician visits and 2 prescription drugs. For those with a chronic condition and functional limitation, 34% were hospitalized and the average patient had 11 home care visits, 8 physician visits, and 22 prescription drugs. For those with 3 or more chronic conditions and severe functional limitation, 44% were hospitalized and the average patient had 12 physician visits, 60 home care visits, and 34 prescription drugs [4].

In 2000, 20% of patients age 65 and over experienced a hospital admission and 30% had an emergency department visit; coordination is always needed following such encounters [6]. Post hospital transfers can be complicated or uncomplicated. Uncomplicated transfers involve one or more transitions from a higher to a lower intensity care setting. Complicated transfers are characterized by transitions back up to a higher or similar level setting or transitions not ending in return to community-based living. Complicated transfers can be considered care failures since the patient is not continuously improving and because costs are high. In one survey, 31% of patients experienced more than one transfer in the 30-day post hospital period. 22-25% of Medicare hospital discharges in 1997 and 1998 were judged as complicated. As expected, patients with older age, more chronic conditions, and more functional disability were at risk for complicated transfers. [7].

Coordinating care: how are we doing?

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Sidebar: Fictional patient vignettes

Mrs. Polley sees a dermatologist for her psoriasis, an orthopedist for her back pain, a gastroenterologist for her GERD and a cardiologist for her hypertension. Mrs. Polley does not have a medical home and has received little information on her medical problems. Her doctors tell her what to do and she tries to do it; she is not involved in the decisions. The cardiologist refers her to a nephrologist for a rising creatinine. Because Mrs. Polley self-referred herself to the orthopedist, neither the cardiologist nor the gastroenterologist are aware that the orthopedist placed Mrs. Polley on high-dose NSAIDs – probably the cause of her GI problems and her rising creatinine.

Jennifer, age 16, is on phenytoin for a seizure disorder. Because she was poorly controlled, her PCP referred her to a neurologist who added carbamazapine. Jennifer became sleepy while driving and sustained multiple rib fractures in an auto accident. The admitting physician contacted the primary care physician who was not aware of the carbamazapine, and only reported the phenytoin to the hospital. On her third hospital day she sustained a seizure, a fractured rib punctured her lung, and she had a hemopneumothorax.

Juan Corazon was sent home from the hospital on 6 diabetes and congestive heart failure drugs. One of his new medications was not on his insurance formulary and he did not obtain it; the pharmacy contacted the hospitalist about this problem but she was off call and the information was not acted on. Mr. Corazon was readmitted in pulmonary edema 3 days later.

Beatrice Nelson, who lived alone, was taking 5 medications from 3 different physicians. Her primary care nurse practitioner took great pains that each provider – 2 specialists, a pharmacist, and a home nurse – was well informed about any medication changes. However, no one made sure that Ms. Nelson herself understood the medications she was taking. She went to the emergency department for nausea and vomiting at 2 AM early Saturday morning. She forgot to take her pills with her, and was not able to describe her medications to the emergency department physician. He tried to contact the PCP on call for the nurse practitioner. Since the practice had no EMR that could be accessed from the physician's home, the PCP did not know the medications. Ms. Nelson did not receive her warfarin and on Monday morning developed a deep vein thrombosis.

The morning of Kay Edwards' discharge from the hospital, a potassium level was ordered from the hospital lab; the value, 5.5 – up from 4.2 two days before – was entered into her hospital chart after she had gone home. No one saw the lab value and the hospital discharge summary was not sent to the primary care physician for a week. The day before the discharge summary reached the primary care physician, Ms. Edwards died of a cardiac arrhythmia, presumably from increasing hyperkalemia.

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Many studies examine the record of the US and Canadian health systems in coordinating care. Given the wide variety of research designs, a systematic review of these studies is not possible. What follows is a sampling of studies, selected by searching "coordination of care" in the Library of Medicine data base for the past 5 years and adding pertinent citations found in those articles. This assessment of care coordination comes both from research sources and patients' voices.

<u>Patients' voices</u>

Harrison et al. [8] interviewed 33 patients discharged from a Canadian hospital describing both positive and negative experiences. 2 negative comments are:

> 39 year-old patient: “I’ve basically kind of fixed up most of it myself. I think what it comes down to is who’s the coordinator? The coordinator seems to be me, the customer.“

> 76 year-old patient: “Don’t leave it to them. Take your situation in your own hands. You have to take your situation in your own hands.”

In 2006, a group of oncologists at Massachusetts General Hospital published an article [9] featuring the voices of patients:

> “My husband, Doug, died recently after a sudden illness...the cardiologist told me that Doug was doing reasonably well, and I naively took solace in this mild pronouncement. That is, until a lung specialist zipped into the room, put his stethoscope to Doug’s chest and said, “He’s not getting better. He’s worse. He may die. Any questions?”

> “My dog was recently admitted to a veterinary hospital and I can’t tell you how different the experience was from my clinical care. The veterinarian called me every single day and told me how my dog was doing and what the plan was for that day. When I was admitted to …[the hospital] it was very difficult to get information.”

The United Hospital Fund of New York published a book “Rough Crossings” including the voices of family caregivers [10]. Many of the examples involve provider-family care coordination:

> The wife of a patient with a recent stroke had received little training in how to use the feeding tube after discharge. “I was terrified of it…When we left the hospital they showed me 1,2,3 and that’s it.” When she was told to be understanding, she retorted, “How can you be understanding when you don’t understand?”

> “When you buy a pet at the pet store, you are given written instructions about how to take care of it, but you get nothing when you take a parent home from the hospital.”

> “The last time my boyfriend was in the hospital…every new staff person who came into the room – the neurologist, the internist, the psychiatrist, and the nurses – all asked questions trying to find out what was going on, but never spoke with each other. “

<u>Coordination problems among providers</u>

Several studies examine coordination of care in the process of referrals from PCPs to specialists. A study of referrals by 122 pediatricians in 34 states found that no information was sent to the specialist in 49% of referrals. The referring physician received feedback from the specialist 55% of the time. Only 62% of letters from specialists included treatment suggestions and only 31% discussed who would be responsible for continued management of the patient [11]. Similar findings come from a 2006 study showing that general pediatricians communicated to specialists only 50% of the time, while specialists sent feedback to the PCP 84% of time within 1 month. In 45% of referrals lacking communication, the specialist was unable to provide optimal care [12].

In a study of the referral process for adults at a US academic medical center, 28% of PCPs and 43% of specialists were dissatisfied with the quality of information they received from each other. For 68% of referrals, specialists reported that they had received no information from the PCP. 25% of the time, specialist consultation reports had not reached the PCP 4 weeks after the specialty visit. 50% of PCPs were dissatisfied with the timeliness of specialists' consultation reports. Lack of time was felt to be an important contributor to the dysfunctional referral process [13]. In a study of referrals of mostly adult patients from community-based family physicians, specialists sent feedback 55% of the time; however, at least 14% of the patients never made their specialist appointment [14].

More visits in the US take place to alternative practitioners such as chiropractors than to PCPs and most people seeing chiropractors also see PCPs; only 25% of chiropractors receive information from PCPs and vice versa [15].

PCPs in 32 Colorado primary care sites reported that clinical information was missing in 14% of visits, resulting in delayed care, potentially adverse consequences for patients, and significant time spent searching for the missing information [16].

In almost 33% of emergency department visits studied, information including medical history and laboratory results was absent. In half the cases the information was essential to patient care [17].

In 2004, a representative survey of US adults found that 30% of people seen in the emergency department (ED) reported that their regular physician did not seem informed about the care received in the ED. 17% of patients who had visited at least 1 physician in the previous 2 years reported that test results or medical records were not available at the time of a scheduled appointment. 14% reported that a physician had ordered an unnecessary test because the physician did not have access to the same test already performed [18].

A similar 2005 survey was performed of US adults with chronic illness or with a recent acute illness. One-third of those who had been hospitalized in the previous 2 years reported that no follow-up care arrangements had been made following hospital discharge. Adults with chronic illness who had seen a physician in the previous 2 years reported test results or medical records were not available at the time of a scheduled visit -- or the physician unnecessarily ordered a duplicate test -- 22% of the time for patients seeing 1 physician and 43% of the time for patients seeing 4 or more physicians [19].

On a given day on an inpatient service, only 48% of the physicians talked to the RN on their team and in only 13% of cases did the MD and RN have complete agreement on the care priorities for the day [20].

One study found that fewer than half of PCPs are provided information about the discharge plans and medications of their recently hospitalized patients [21]. A literature review of information transfer between hospital-based and primary care physicians found that only 3% of PCPs were involved in discussions with hospital physicians about patients' discharge plans; 17-20% were always notified that the patient had been discharged; and fewer than 20% had received a discharge summary one week following discharge. 25% of discharge summaries never reached the PCPs, 38% of discharge summaries did not include reports of lab results, and 21% did not list discharge medications. In over 66% of cases, PCPs contacted or treated post-hospital patients before receiving a discharge summary, adversely affecting the care of 24% of patients [22].

At a Canadian hospital in 2003, 54% of patients on at least 4 pre-admission medications had a discrepancy between their pre-admission medications and their admitting medication orders; 39% were potentially serious and almost half the discrepancies involved omission of a regular pre-admission medication [23]. For only 12% of patients discharged from a Canadian hospital was the hospital discharge summary available at the time of the first post-hospital physician visit [24].

This brief review has not chronicled the impact of care coordination problems on medical errors, patient outcomes, or costs. An emerging literature is addressing this issue. Overall, investigators of care coordination feel that lack of timely information exchange among providers threatens quality and patient safety, and that "Poorly executed care transitions can further lead to greater use of hospital and emergency services, increasing healthcare costs [25]. One example is a 2003 study demonstrating that 19% of patients had adverse events following discharge from a US teaching hospital. 62% were avoidable events, many of which were related to inadequate communication with the follow-up physician and patient. [26].

Coordination problems between providers and patients/families

75% of physicians do not routinely contact patients about normal diagnostic test results and up to 33% do not consistently notify patients of abnormal results [17].

According to a 2000 national survey, approximately 20 million people with chronic illnesses received contradictory information from different health care providers during the year [3]. In a 2004 survey, 18% of people who had utilized physician services during the previous 2 years reported receiving conflicting information from different doctors. 24% reported leaving a physician visit with important questions unanswered. 41% of those taking prescription medications regularly reported that their physician had not reviewed their medications or had not explained medication side effects. 20% reported not finding out the results of a diagnostic test, or having an unclear explanation of the results [18].

In a 2005 survey, 17% of adults hospitalized in the previous 2 years reported that information about their care had not been communicated to them. 27% said that the hospital had not made arrangements for a follow-up physician visit. 33% of those who used medications prior to the hospital admission and received a new prescription received information on whether or not to take the pre-hospital medications. 23% of patients who had lab tests performed reported delays in being notified about abnormal test results or receiving inaccurate information on lab tests. 48% reported not routinely getting information about medication side effects [19].

In focus groups and satisfaction surveys, patients and families have consistently reported being unprepared for transitions between one setting and another [6].

How do we measure care coordination quality?

The care coordination measure endorsed by the National Quality Forum is the 3-item Care Transitions Measure (CTM-3), developed by Eric Coleman [27]. The three-item measure is derived from a 15-question measure, but the three items account for over 80% of the variance within the 15-item scores. The measure is specific to hospital discharge care coordination and focuses on patients' understanding of their care plan. A variety of other measures have been proposed for other coordination domains, for example referral from PCP to specialist, medication reconciliation, and follow-up of diagnostic tests [28].

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CTM-3

1. The hospital staff took my preferences and those of my family or caregiver into account in deciding ***what*** my health care needs would be when I left the hospital.

Strongly Disagree Disagree Agree Strongly Agree Don't Know/ Don't Remember/ Not Applicable

2. When I left the hospital, I had a good understanding of the things I was responsible for in managing my health.

Strongly Disagree Disagree Agree Strongly Agree Don't Know/ Don't Remember/ Not Applicable

3. When I left the hospital, I clearly understood the purpose for taking each of my medications.

Strongly Disagree Disagree Agree Strongly Agree Don't Know/ Don't Remember/ Not Applicable

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What are the major barriers to seamless care coordination

The overstressed primary care medical home

Care coordination is virtually impossible without a strong primary care foundation to the health care system – a medical home for each person and family. This foundation is crumbling. Between 1997 and 2006, the number of US medical graduates choosing family medicine careers dropped by 50%. In 1998, 54% of internal medicine residents selected primary care careers; by 2005 only 20% were going into primary care with the remainder becoming subspecialists or hospitalists [29]. Primary care performance on chronic disease processes and outcomes and preventive services are substandard [30-33]. With large patient panels, and a growing number of tasks to perform for each patient, primary care physicians can no longer provide high-quality acute, chronic and preventive care in the 15 minute visit, let alone perform care coordination functions for which they are not reimbursed [29].

The uninformed, passive patient

In a study of 264 audiotaped visits to family physicians, patients making an initial statement of their problem were interrupted after an average of 23 seconds. In 25% of the visits the physician never asked the patient for his/her concerns at all [34]. In a 1994 study, 76% of patients with non-insulin dependent type 2 diabetes received limited or no diabetes education

[35]. In an audiotaped study of 336 medical encounters with 34 physicians, doctors devoted an average of 1.3 minutes to giving information, with 88% of the information worded in technical language [36]. While physicians frequently attribute medication nonadherence to patient behavior, in fact three out of four physicians in one study failed to give patients clear instructions on how to take their medications [37,38].

In one study, 50% of patients left the office visit not understanding what they were told by the physician [39]. In another study, when physicians asked patients to restate the physician's instructions, the patients responded incorrectly 47% of the time [40]. A third study reported that 50% of patients, when asked to state how they were supposed to take a prescribed medication, did not understand how the physician had prescribed the medication [41].

Patients are seldom encouraged to be active participants in their care. According to a study of over 1000 audiotaped visits with 124 physicians, patients participated in medical decisions only 9% of the time [42]. 96% of patients surveyed wanted to be offered choices and to be asked their opinion [43]. Patients are more likely to be active participants in their care when their physicians encourage such participation [44]. Active participation in care is associated with healthier behaviors, better chronic disease outcomes and medication adherence and better care coordination [45,46].

All these studies strongly suggest that the health care system insufficiently encourages patients to be informed and activated.

Lack of time

The average duration of primary care physician visits by established patients is 16-18 minutes [47-49]. The tasks primary care physicians must accomplish are far more complex and time-consuming than a decade ago [3]. It has been estimated that it would take a physician 7.4 hours per working day to provide all recommended preventive services to a typical patient panel [50], plus 10.6 hours per day to provide high-quality chronic care [51]. 42% of primary care physicians report not having sufficient time with their patients [52]. Longer visits are associated with better quality indicators for chronic conditions, more health education and improved patient satisfaction [53,54]. Providing information to patients and engaging in shared decision making take more time and thus are insufficiently done in the primary care visit [55,56]. To add care coordination on an already impossible schedule will not work.

Lack of interoperable computerized records

In 2005, only 15-20% of physician offices and 20-25% of hospitals had implemented electronic medical record systems [57]. In few cases can health facilities access electronic information from other facilities in the same geographic area [58]. Care coordination would become much easier were regionally interoperative EMRs a standard feature of US health care.

Dysfunctional financing

The overwhelming majority of public and private insurance dollars are paid to physicians based on quantity rather than quality. One-shot procedures and imaging services are reimbursed at a higher rate per time spent than cognitive services. Moreover, payment is based on face-to-face visit time rather the between-visit time required for much care coordination [59]. Neither hospitals nor primary care physicians have a financial incentive to offer the intensive post-hospital care needed to smooth the often rocky transition between hospital and home. Hospitals may benefit financially from patients being readmitted and thus lack the business case for providing post-hospital care. Pay for performance projects, which generally provide a small percent of physician revenues, are based on specific measures that do not encourage improved quality for the multiple-diagnosis chronically ill patients with functional limitations – those at highest risk of needing care coordination [60].

Lack of integrated systems of care

47% of private physicians work in practices of 1 or 2 physicians; the percentage of physicians in groups of 20 or more did not increase between 1996 and 2001 [61]. It appears that continuity of care is deteriorating, requiring more care coordination, with many patients receiving fragmented care in emergency department or “minute clinics” because they are unable to obtain prompt access to primary care. Quality of primary care, and EMR adoption, is higher in integrated medical groups than in small offices [62]. Care coordination is more difficult for small independent providers who cannot easily access patient records from other independent providers; in contrast, different care sites within integrated organizations can generally access information for care provided within the organization.

On Lok Senior Health Services in San Francisco is perhaps the best example of an integrated system of care that provides superlative care coordination. For over 30 years, On Lok, with its multidisciplinary teams, electronic medical record, capitated payment, and complete range of services – including transportation, housing, meals, adult day health services, and geriatric aides who make frequent home visits – is able to provide seamless transitions for nursing home-eligible frail elders at lower cost than usual care. On Lok became the model for similar institutions around the US through the Program of All-Inclusive Care for the Elderly (PACE) [63].

Lack of quality improvement that is patient/family-centered

Quality improvement is site-limited; i.e. a physician practice will improve the care of patients with diabetes or a hospital will do better in preventing surgical wound infections. Rarely is the unit of interest the patient. An exception is the Esther project of the Jonkoping County, Sweden health system. Esther is an elderly woman with heart failure who lives on the third floor and cannot get down the stairs. She is a fictional patient, yet millions of Esthers live throughout the planet. Viewing care from the perspective of Esther, rather than from the experience of a nurse or physician at a particular site, dramatically expands the horizon of improvement work. In Jonkoping County, meetings to improve Esther’s care are attended by physicians, nurses, social workers, physical and occupational therapists, and home care attendants representing many in-hospital, out-patient, transportation, emergency, and assisted living units. Dramatic results followed the introduction of this new paradigm of patient-centered quality improvement [64].

How do we fix our care coordination failures?

A number of studies have demonstrated that focused interventions in a research environment can improve care coordination [22]. Several organizations have promulgated care coordination guidelines. Given the profound nature of the barriers listed above, these interventions and guidelines are unrealistic. One can recommend, beg, or require a primary care physician to perform the care coordination function that is an integral part of primary care. But given the panel sizes, unrelenting demands, and inadequate reimbursement of many primary care physicians, research findings, entreaties or mandates will go unheeded.

In part due primary care's inadequacy in serving as the coordinating hub for patients needing care coordination, a large disease management industry has sprung up, one of whose activities is the coordination of care for patients with chronic conditions. Some disease management programs appear to be effective in improving chronic disease measures, but evidence that these programs improve care coordination is inconclusive [65]. A problem with the disease management industry is that it creates yet another health care entity that requires coordination with PCPs, specialists, pharmacies, and other providers, thereby complicating an already overly complicated system. The coordinating function would be more logically performed in health care's coordinating hub which should be the primary care practice. If all the moneys paid to the disease management industry were paid to primary care to accomplish the same work, care coordination might become simpler and the need for regular communication between a disease management company and its patients' numerous primary care practices would be obviated.

To solve the care coordination problem we need to overcome the daunting barriers by instituting fundamental health system reform. This is not to say that nothing can be done short of revolution. We can begin with one health plan changing reimbursement, one practice transforming primary care, and one standard-setting body such as ABIM offering concrete assistance. The following list of 5 reforms needed to improve care coordination are derived from the list of barriers described above.

<u>A transformed primary care medical home</u>

The transformed primary care medical home addresses the first 3 barriers: problems with primary care, uninformed passive patients, and lack of time. The medical home is the site responsible to ensure that care is coordinated, both among providers and between providers and patients/families. Without a medical home, no entity assumes the responsibility to coordinate care. With a medical home, that responsibility lies jointly with the primary care provider team and with patients and families whom the provider team must assist to be informed and activated. Without a medical home in which all clinical information about patients/families resides, the information is scattered to the winds. With a medical home, the primary care provider team is responsible to gather all information from all sites dealing with the patient/family and to impart that information in understandable form to the patient/family. The primary care home and the patient/family constitute a partnership who share responsibility for coordinating care.

If patients expect to receive high quality and coordinated care, they have to do their part and sign up for a primary care medical home. During the height of the managed care era, tens of millions of people were required to choose a primary care practice. That was a positive development created by managed care. The negative aspect was that PCPs were empowered by insurers to deny insurance-paid access to specialists and other sites in the health system. In the transformed medical home concept, patients are required to choose a medical home, can freely change their medical home, and the medical home cannot deny payment for specialty and other referrals. If all patients are required to have a medical home, care coordination becomes easier.

The medical home is responsible to do all possible to assist patients/families to be informed, active participants in the health care process. Patients and families with complex illnesses have reported that they want to play a substantial role in coordination of care [66].

<u>Assisting patients to be informed and activated</u>. To make sure that patients are informed requires at a minimum that “closing the loop” takes place after each medical encounter. Closing the loop is a simple activity that addressed the disturbing fact that 50% of patients do not understand advice given by the clinician [40]. Closing the loop means asking the patient to actively state their understanding of advice given by the clinician. If the patient gets it wrong (which about 50% will), they are corrected until they truly understand. Closing the loop has been associated with improved outcomes in patients with diabetes [40].

To encourage patients to be activated participants is more challenging. Patients must be allowed to add their agenda items for the medical encounter to the agenda of the clinician. They must be engaged in shared decision-making. They must have the opportunity to ask questions. And patients/families must be trained in disease-specific skills that give them confidence that they can be part of the care process.

How can all this happen when primary care does not have the time to provide consistent high quality chronic and preventive care and when patients are increasingly reporting that their primary care physicians don’t even know who they are [67]. This is where the transformed medical home comes in.

<u>The teamlet model</u>. The fundamental pathology of primary care is the 15 minute clinician visit, into which the entire health care process is concentrated. The transformed primary care home expands the 15-minute visit into a longer encounter. The longer encounter is not only with the clinician, but with two people, the clinician plus an additional staff person who could be called a coach, a navigator, a coordinator, or any other appropriate title. (We will use the name “coach” in this discussion.) [68,69]. Because the clinician and coach make up a small team that is only part of the larger teams that exist in some primary care practices, this small two-person team is called a team*let*. The coach would ideally be a RN or advanced practice clinician, but most practices do not have these personnel available. Medical assistants, who work in almost every primary care practice in the US, could be trained to take on the functions of a coach.

How does the expanded encounter look? It consists of pre-visit, visit, post-visit, and between-visit care. Details of what takes place in each of these parts of the encounter have been described elsewhere [68]. Pertinent to the topic of care coordination are tasks that can be performed by the coach during post-visit and between-visit care. In the post-visit, the coach closes the loop to make sure the patient understands advice given by the clinician. The coach also checks to make sure the patient agrees with the clinician’s advice. (Shared decision making is a key determinant of the activated patient and shared decision making rarely happens in the 15 minute visit because it increases visit time). If the patient does not agree, the coach needs to reconnect with the clinician to determine how to proceed. Finally, the coach is responsible for care coordination both between provider and patient and among providers. Part of between-visit care is informing patients of all lab and other diagnostic test values and making sure patients understand what these values mean, For any referrals to other parts of the health care system, the coach makes sure the patient/family understands how to navigate the system, is responsible that referrals to specialists and diagnostic testing include all needed information, and makes sure that consultation reports come back from specialists and that results are transmitted to patients, These coach functions require good reminder systems and check lists. But no matter how many reminder systems and checklists are devised, asking clinicians to perform these functions will not work due to lack of time and competing demands. Each clinician-coach teamlet will work out which functions the coach is competent to perform; the clinician must be confident in the coach's ability before delegating any task. Because the teamlet duo works side by side, coaches can easily consult with clinicians for any situations they are not trained or authorized to handle.

The teamlet model places the responsibility on the coach to ensure that care coordination takes place in 3 domains: 1) that patients/families are informed of everything that happens, 2) that proper information flows from the primary care home to referral sites, and 3) that other sites where patients receive care are contacted to make sure that they send back all information in a timely manner. One might ask: what if other sites do not inform the primary care home that a patient was seen? The answer is: the informed activated patient and family. As an integral part of the medical home, patients/families assume the responsibility to inform the primary care home of medical care provided elsewhere.

<u>Is primary care needed?</u> One might ask, given the difficulties of improving primary care, is primary care truly essential for good care coordination? The problem with diffusing this responsibility among many sites is that 1) each site would need to know all other sites caring for the patient and 2) information would need to be exchanged among all those sites, requiring many more information exchange transactions. Having a primary care hub for information flow is more efficient and clarifies exactly who is responsible – the primary care home including the patient/family –- for the care coordination function. If someone is not responsible, no one is responsible.

Could one envision a system in which only the patient/family assume full responsibility for coordinating care without need for a primary care home? Patients/families would have a personal medical record and take it everywhere they go. However, it is difficult for patients/families to become informed and activated without the assistance of the primary care home. Moreover, primary care is needed to interpret and discuss the sometimes conflicting advice coming from different care providers. Some well-educated and activated patients without complex medical issues could be their own coordinators. But those at most risk for needing coordinated care – with multiple chronic illnesses, several physicians, and many medications – are often the least able to be their own coordinators. Thus the partnership between primary care and the patient/family is essential.

<u>Interoperable computerized records</u>

Every health care facility should have an EMR, all EMRs should be able to talk to each other, and a care provider in any site should be able – with the patient's permission – to instantaneously electronically access all information about the patient from all sites, ideally from a centralized data repository. Given the existence of the internet, there is no technical reason why this could not happen tomorrow. Indianapolis, through the work of the Regenstrief Institute and Indiana Health Information Exchange has thus far been the leader in this process [70].

Fixing primary care financing

Some of primary care's difficulties are caused by a lack of sufficient and well-designed financing; financing is also one reason why the United States is so far behind most developed nations in computerizing patient information.

Proposals abound for fixing this problem; the most thoughtful concept is that put forward by Goroll and others [71]. Instead of fee-for-service payments, the medical home would receive a comprehensive risk-adjusted payment per patient. Some of the payment would support physician income, but a considerable portion would be dedicated to the creation of a strong primary care team, with additional amounts for computerizing the practice and for performance bonuses. Practices would need to be demonstrate that they deserve this new comprehensive payment, including the assumption of responsibility for coordinating the care of their patients throughout the health care system.

This proposal makes feasible the teamlet transformation of primary care in which a coach, working hand-in-hand with the clinician, performs many care coordination tasks. Under fee-for-service reimbursement, coaches are an additional expense without generating any revenue. Under the comprehensive payment reform, funds are dedicated for practices to hire, train, and adequately pay coaches to perform the routine, day-in and day-out, reminder-prompted and check-list-driven work of care coordination. Moreover, under the risk-adjusted payment feature, extra funds are provided precisely for those patients at high risk of needing extensive care coordination.

These proposals do not address other payment dysfunctions in the system, for example that hospitals have no incentive to provide the post-hospital care that has been shown repeatedly to prevent errors, improve outcomes and reduce costly rehospitalizations. The efforts of highly-trained hospital-based coaches proposed by Eric Coleman [46] may be needed for the critically important post-discharge period; primary care teamlet coaches, unless they are RNs, can not handle that level of care.

Integrated systems of care

Lack of integrated provider systems is one of the barriers to good care coordination. Fixing primary care is daunting enough; imagine transforming all health care into integrated delivery systems.

If we are to fix care coordination short of creating integrated delivery systems, there are two fundamental changes we must make. These are the changes proposed by Eric Coleman in his transitions intervention.

Sometimes a thought leader appears who transforms the understanding of a particular issue. For chronic care, that thought leader is Ed Wagner. As I have begun to learn about the issue of care coordination, the person who has provided me with the most profound understanding of the topic is Eric Coleman. His work on transitions, buttressed by the studies of Mary Naylor and others [72], goes well beyond a limited intervention based on one small research study and transcends all the protocols and check lists that have been developed for coordinating care. Dr. Coleman understood that two simple things are needed to solve the problem of care coordination: patient activation and coaches. He recognized that many care coordination problems could be solved by the only party that is present both before and after a handoff or transition takes place: the patient and family. He also saw that one cannot expect a busy, stressed clinician to take care of care coordination; just as primary care needs teamlet coaches, other institutions need coaches to perform coordination functions. Dr. Coleman realized that the job of the coaches was not only to do the care coordination work, but more importantly to train patients and families to learn to do the care coordination work themselves. If those two principles – coaches and actively participating patients and families – were implemented in every institution, perhaps one could solve care coordination problems without integration [25, 46].

Patient/family-centered quality improvement work

The example of the Esther project in Sweden [65] suggests a paradigm for a new type of quality improvement work. It is not enough to fix diabetes care at a community health center or to implement same-day access at a cardiology out-patient clinic. The Esther paradigm looks at a patient's patterns of using the health care system, uncovers the problems, brings together appropriate people from all sites caring for the patient, and solves the problems in a system-wide rather than site-specific manner. By its very nature, most care coordination does not take place within sites; it happens between sites.

How do we start?

The list of things we need to change to perform consistent high-quality care coordination are frightening in their scope. But we need to make those system changes for many reasons, not just to improve care coordination. Let me conclude with 3 simple thoughts about how to start.

First, this is not research. This is quality improvement. It needs an evaluation component, but it is not a research project. More research grants with budgets and research assistants and excluding certain categories of patients is not what we need. We need changes that are scalable to the entire health care system and financially sustainable through a stable payment mechanism.

Second, we start with microsystem improvement. Create a primary care practice that has coaches, that teaches and encourages patients to be informed and activated, and train those coaches to coordinate care. Do a simple evaluation, and disseminate the results as broadly as possible so that others can replicate the work and improve on it. A great deal of such experimentation is going on, though good ideas are not broadly disseminated because widely-read journals rarely publish this work. The ABIM Foundation could consider playing a role in new ways of spreading microsystem improvement ideas.

Third and simultaneously, we have to undertake serious macrosystem improvement – a national campaign for payment reform. Primary care organizations are coalescing with others, including large employer partners, to address this issue. The ABIM Foundation could play a role in such a coalition.

Just as primary care practices need time to provide the best care coordination, we need leaders with time to engage in macrosystem payment reform that creates strong incentives for microsystem transformation. With enough people with enough time, we can do it.

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