

Coordinating Care across Diseases, Settings, and Clinicians: A Key Role for the Generalist in Practice

Christopher J. Stille, MD, MPH; Anthony Jerant, MD; Douglas Bell, MD, PhD; David Meltzer, MD, PhD; and Joann G. Elmore, MD, MPH

Coordinated care is a defining principle of primary care, but it is becoming increasingly difficult to provide as the health care delivery system in the United States becomes more complex. To guide recommendations for research and practice, the evidence about implementation of coordinated care and its benefits must be considered. On the basis of review of the published literature this article makes recommendations concerning needs for a better-developed evidence base to substantiate the value of care coordination, generalist practices to be the hub of care coordination for most patients, improved communication among clinicians, a

team approach to achieve coordination, integration of patients and families as partners, and incorporation of medical informatics. Although coordination of care is central to generalist practice, it requires far more effort than physicians alone can deliver. To make policy recommendations, further work is needed to identify essential elements of care coordination and prove its effectiveness at improving health outcomes.

Ann Intern Med. 2005;142:700-708.

www.annals.org

For author affiliations, see end of text.

The goal of coordination of medical care is to support patients and their families in their efforts to receive effective health care from an increasingly complex health care system. Coordination involves “the regulation of diverse elements into an integrated and harmonious operation” (1). Starfield (2) describes the essence of health care coordination as “the availability of information about prior problems and services and the recognition of that information as it bears on needs for current care.” This information includes knowledge about patients and families, and their experiences with and responses to health care. Ideally, information is made available through easily accessible medical records; written and verbal communication among clinicians, patients, families, and community resources; and clinicians’ knowledge gained from past experiences with patients.

Medical advances have created the need for coordination of care by contributing to greater longevity, and because chronic illnesses become more prevalent with aging, more patients experience more health conditions. As the knowledge base required to practice medicine has increased, it has become impossible for any one physician to possess all the information needed to care for a patient, resulting in the need for medical specialization and coordination of care among multiple specialists (3). Furthermore, medical care is being provided in a greater variety of settings, including nonphysician provider offices, nursing facilities, and patients’ homes. Coordination of activities across care settings is therefore needed.

Coordination of medical care, a core function of primary care (2), is embraced by generalist physicians as a defining principle of their work (4–6). Generalists are well positioned to care for the many patients whose conditions do not fall neatly into a single disease category (4, 7, 8). The structure of generalist practice does not easily lend itself to coordination of care, although relatively small changes could help this greatly.

The scenarios in the Appendix, which are adapted from a report by the Institute of Medicine (9), provide

dramatic examples of coordinated care on clinical outcomes. Scenario 1 demonstrates a team approach to care coordination, in which clinicians and staff play differing roles depending on their expertise. In contrast, scenario 2 depicts elements of fragmented care that are commonly seen. We review the literature on coordination of care and its effectiveness and make recommendations for generalist research, education, and practice.

METHODS

In 2003, the Robert Wood Johnson Foundation Generalist Physician Faculty Scholars program asked current and past grantees and National Advisory Committee members to consider several topics, including coordination of care, and their implications for the future of generalist research, education, and practice. A volunteer group of 5 physicians (3 from general internal medicine and 1 each from family medicine and pediatrics) was formed, on the basis of interest in the topic and representation from each generalist discipline, to review the literature on coordination of care and make recommendations. A series of 5 telephone conference calls and more frequent electronic mail correspondence took place over 6 months. The group chose to study the following questions from the point of view of the generalist physician’s practice:

1. What evidence exists that care coordination improves health care?
2. What role should the generalist practice play in care coordination?
3. What improvements, if any, should be made in collaboration among generalist and subspecialty physicians?

See also:

Web-Only

Conversion of figure and tables into slides

4. How should teams be structured to provide optimally coordinated care?

5. What is the role of patients and families in care coordination?

6. How can medical informatics contribute to care coordination?

After reviewing the current literature, the working group formulated 6 key recommendations and pointed out gaps where more research is needed before recommendations could be made. Findings from the published literature were incorporated whenever possible. At the 2003 national grantees' meeting, these recommendations were discussed by a group of more than 100 scholars, mentors, and nationally acknowledged experts on generalist physician practice. The literature review and recommendations were subsequently refined and incorporated into this article.

The Robert Wood Johnson Foundation Generalist Faculty Scholars Program and the National Center for Research Resources provided funding for investigators' time to conduct and report on this study. The funding agencies played no role in the design, conduct, or reporting of the study.

RESULTS

Consensus Recommendations

1. *More evidence is needed to substantiate the value of care coordination in improving health outcomes and to identify the most useful components to be included in models of care coordination.*

Recommending "optimal" approaches to coordinated care is difficult because of several factors: no agreement about what constitutes "coordinated care"; the need for a core set of outcomes of coordination that are measurable and sensitive to change, but also relevant to patient care; few published studies on the complex populations that may benefit most from improved coordination; and few studies aimed at determining which coordination activities might be most useful. Although the terms are often used interchangeably, many interventions that have been described as "coordinated care" (10, 11–13) actually concern collaborative care. Collaboration is simply the act of working together (1), whereas coordination involves regulation of participants to produce higher-order functioning. It requires developing and guiding a therapeutic plan and integrating the inputs of multiple clinicians, patients, and families (and, at times, community agencies, employers, or schools) toward a common goal.

Table 1 summarizes studies on coordinated care. This table is not an exhaustive list; rather, it represents the best interventions in the outpatient setting for a variety of age groups and conditions. Some studies (12, 14, 15) involved personnel dedicated to coordinating care, whereas others examined only collaboration between primary care and specialty physicians.

Most studies that reported positive results evaluated

the effect of interventions on health care outcomes (10, 11, 14, 15), such as appropriate utilization of care. In contrast, studies that examined health outcomes tended to report mixed results (12, 13, 16–18). Although the obvious goal of improving health services is to improve health, the immediate target of interventions to improve coordination is not a disease process but rather the health care system. Immediate improvements might include better access to care, more timely care, more accurate plans, fewer medical errors, and increased patient participation. These factors are difficult to measure, although resultant improvements in utilization can be measured and quantified. Improvements in health resulting from changes in the system of health care are mediated through improvements in health care delivery, and evaluation that focuses only on health outcomes may not recognize beneficial changes to the health care system that are necessary but not sufficient to improve health outcomes.

Most studies investigating the impact of coordination of care were limited to patients with a single disease, which decreases their ability to show changes in outcomes resulting from improved coordination of care for patients with complex needs. Demonstration projects focusing on groups of patients with 1 or more comorbid conditions, which account for the majority of visits by patients with chronic conditions (19), might prove more useful in measuring the value of care coordination.

Defining which elements of care coordination are critical for improving health outcomes and operationalizing them for implementation and study have yet to be achieved. Some argue that better quality measures are needed to measure outcomes associated with generalist care functions (20). The need for improved measures is illustrated by an effort to coordinate care for children with chronic conditions in primary care settings. Investigators found that families had many unmet needs that were unsuspected by their pediatrician (21). In this case, increased reporting of unmet needs might be a positive outcome because unmet but newly recognized needs can be targeted with future interventions. Intermediate outcomes, such as the family's sense that their needs have been heard, are also very important. Coordinated care remains a core value of primary care and generalist practice, but more evidence linking these intuitively valuable results, improvements in health care outcomes, and health outcomes is needed to demonstrate its value to policymakers and payors as a necessary component of the health care system.

2. *The generalist physician's practice is an appropriate hub for the medical aspects of care coordination for most patients.*

Health care is increasingly being provided by teams, whose members have differing expertise in the many tasks needed to provide high-quality care. As a team grows in size, communication becomes much more complex. The maximum number of lines of communication is nonlinear,

Table 1. Examples of Collaborative Care and Coordinated Care

Study, Year (Reference)	Type of Patient	Intervention	Participants	Main Outcome	Effect
Schillinger et al., 2000 (11)	Adult general medicine	Gatekeeping (authorization required for specialty care)	Primary care physicians	Use of ambulatory care, emergency department, and hospital	Increased visits to primary care physician, decreased use of specialty care and hospital
Addington-Hall et al., 1992 (12)	Terminally ill adults with cancer	Coordinated care	Registered nurses	Symptoms, psychiatric illness, service use	Less cough and vomiting; more use of chiropractic
Weinberger et al., 1995 (13)	Adults with type 2 diabetes mellitus	Telephone contact with nurse-coordinators	Registered nurses	Glycemic control (glycosylated hemoglobin level), health-related quality of life (Medical Outcomes Study 36-Item Short Form Health Survey)	Modest decrease in glycosylated hemoglobin level; no change in SF-36 variables
Kisker et al., 1997 (10)	Pediatric cancer	Shared management protocol with decision support for primary care	Community Primary care physicians, academic oncologists	Mortality, morbidity, protocol adherence, costs to families	Improved access to care; decreased costs; no decrease in morbidity, mortality, or protocol adherence
Palfrey, 2004 (15)	Children with complex medical or developmental needs	Multifaceted intervention, including nurse practitioner as care coordinator, individualized health plans	Community Primary care physicians, parents, nurse practitioner	Access to appropriate services, satisfaction, hospitalization rates, missed parental work days	Improved access to services, fewer hospitalizations and missed work days; no change in satisfaction
Katon et al., 1995 (18)	Adults with depression	Management in primary care with 2 primary care physician visits and 2 psychiatrist visits	Primary care physicians, psychiatrists	Depressive symptoms, adherence to antidepressant therapy, satisfaction	Statistically significant improvement in all outcomes
Katon et al., 1999 (16); Katon et al., 2002 (17)	Adults with depression persisting after 6 to 8 weeks of antidepressant therapy	Education, psychiatry visits	Primary care physicians and psychiatrists	Depressive symptoms, adherence to antidepressant therapy, satisfaction	Statistically significant improvement in all outcomes; improvement in symptoms persisted at 2 years
Unutzer et al., 2002 (14)	Adults age ≥ 60 y with depression	Supervised depression care manager	Care manager, psychiatrist, primary care physician	Depressive symptoms, functional impairment, treatment rates	Statistically significant improvement in all outcomes

as described by the equation $(n^2 - n)/2$, where n is the number of team members (22). Thus, on a team with 5 members, 10 lines of communication are possible. It is easy to assemble a team of at least this size: For instance, a team that cares for a patient with a simple, chronic orthopedic condition might include at a minimum the patient, a family member, generalist and orthopedic physicians, and a physical therapist. To help simplify and streamline communication, care coordination models put 1 clinician at the center of the network, so that other team members are generally required to communicate only with the single coordinating clinician and patients and families can receive a coherent message.

Generalist physicians and their practices are best positioned to oversee coordination of care in this model. They have the advantages of medical knowledge and training in caring for the “whole” patient and family, rather than focusing on 1 organ system or disease process. Residency curricula in family medicine and pediatrics stress this approach to care in their outpatient training requirements (5), and the Society of General Internal Medicine has recommended it for future changes in training (4). Most patients who require care coordination have several problems (19, 23), requiring integration of input from multiple sources into a clear message for the patient and family (8). Generalist physicians are interpreters of the multiple “lan-

guages" spoken on the health care team. Logistically, the generalist physician is often the physician who is most accessible to the patient and who has knowledge of the patient's community. Although specific aspects of coordination, such as involvement with community agencies, may be better provided by others within the generalist's practice team, generalists are aware of community supports and challenges (24) and are well equipped to provide a "medical home" for patients with chronic conditions (7). Implicit in this model is the idea that the generalist physician has enough knowledge to understand the implications of the disparate pieces of information he or she receives. Acting as care coordinator is both intellectually demanding and time-consuming.

Other programs for chronic disease management that are dedicated to coordinating care for a single disease (such as asthma) or a segment of the population (such as Medicaid-insured children with complex health care needs) have been promoted as ways to improve care and make more efficient use of resources. This type of program may sometimes strengthen coordinating roles otherwise taken on by generalist physicians and may serve as an educational and quality improvement tool for generalists. However, these programs may conflict as patients develop multiple chronic conditions, emphasizing the need for coordination of care by a knowledgeable professional.

Coordination of care takes time. Activities such as filling out forms and speaking with other health care providers, community agencies, and schools occupy large amounts of physician time, with little compensation. Some tasks may be handled well by a system that includes non-physician members of the practice team, including administrative staff or, ideally, designated care coordinators. This activity must be supported by payors. Some mechanisms exist for reimbursement, although they are underused (7). Research is under way to quantify the time and cost of these care coordination activities so that arguments can be made for increased compensation for these functions (25).

3. Generalist and specialist physicians must collaborate and communicate more closely to ensure timely, well-planned care.

As the population of the United States ages, more people are living longer, but an increasing number experience chronic disease. It is estimated that 99 million Americans (26), including 15% of children (27), have a chronic condition. Although most people receive treatment from generalist clinicians, specialty care for chronic conditions is frequently required, and more than 1 specialist may be involved. Specific care for individual conditions may have better outcomes when delivered by specialists (28), but primary care remains essential for these patients. The generalist should be involved as more than just a gatekeeper to specialty care; studies have shown that close involvement of generalist clinicians in specialty care leads to more cost-effective care and better health (29–31). Scenario 1 in the

Appendix illustrates well the benefits of this involvement. Information is shared readily by fax between physicians' offices. Many studies in adults and children report that patients and clinicians prefer shared generalist–specialist care for such reasons as access to and continuity of care, and collaborative care programs can work well (10, 14, 32–35).

In the absence of specific programs to link the efforts of generalists and specialists, clinicians often work in parallel rather than collaboratively. This system leaves patients at risk for disjointed, ineffective care. Studies over the past 30 years describe gaps in care for patients with chronic conditions who require specialty consultation (21, 36–38), but finding solutions remains challenging. Communication between generalists and specialists needs improvement, and the timeliness of such communication in particular is a major problem. Studies from general internal medicine and family medicine (39–42) have described rates of communication from specialists back to referring physicians after a consultation that range from 55% to 80%. A recent national study in pediatrics (43) found that referring generalists reported receipt of communication from subspecialists 51% of the time within 3 months after a referral was made, and sharing of care was discussed in only 31% of cases. In another study, pediatricians reported that to facilitate care, communication about nonurgent consultations should occur within 2 weeks after the consultation (44).

Communication from referring generalists to specialists about a referral is an even greater problem. A recent survey of pediatricians in New England reported that fewer than 30% of pediatric specialists receive communication about the majority of patients referred from other physicians (44). Barriers to bidirectional communication cited by both generalists and specialists mainly concerned inefficiencies in the communication system. A single-system study of internists (42) reported that 68% of specialists receive no information from referring physicians before seeing patients. These studies and others (46, 47) highlight the importance of clearly communicating a specific question or reason for referral and represent a major opportunity for improvement in generalist practice.

The chronic care model and other models (46, 47) describe changes in the system of practice that may help boost collaboration. These models, which are frequently used as the basis for quality improvement efforts, advocate integration of patients, families, and the community into the health care system to improve health care outcomes. Visits for chronic illness in which coordination of care is the focus and team meetings during which input from multiple clinicians can be considered are 2 promising strategies derived from this model. A recent successful model involved generalist practices assembling and referring within a "tight web of consultants" (15), in which physicians know one another well and can share work effectively. Most important, education of both generalist and

specialist physicians-in-training must emphasize collaboration between clinicians (4, 48), modeling a team approach to management of chronic illness. Education about collaboration must include skill building in team leadership and negotiation so that consensus may be achieved.

4. Generalist practices must build teams that are relevant and visible to the patients and communities being served, and these teams must be sustainable within the local health care system.

Primary care delivered in the context of a team whose members form a cohesive unit can improve health care outcomes (49). However, the composition of the optimal health care team for coordination of care has yet to be defined. In current generalist practice in the United States, the composition of teams varies greatly among settings. Generalist physicians, practice nurses, and nurses' aides are usually included, but few practices include other personnel (such as generalist office staff, clinical pharmacists, hospitalists, community nurses, and social workers), even though it might improve care coordination (2). A major challenge for generalist practice is to assemble core teams from a long list of "potential players" that are relevant to the patients and communities being served and that are sustainable within the local health care system. **Table 2** describes potential team members who may contribute to the process of care coordination. The core team in almost all cases will include the patient, the primary care physician, 1 or more staff members, and subspecialists; others should be added as needs become more complex. For example, in a general internal medicine practice that serves a generally elderly, low-income Hispanic population, the core team might include a family advocate from the community, general internist, geriatric nurse practitioner, geriatric specialist physician, social worker, and medical interpreter. As many persons on the team as possible will be bilingual. The internist would provide overall team leadership, whereas the social worker would be in charge of most care coordination activities.

Although an inclusive approach to team building could bring valuable perspectives to care and improve its quality, the size of the team must be kept under control, because communication becomes more difficult in larger teams (50). Furthermore, most physicians have little leadership training in or experience with effective team practice (46). To allow effective coordinated care, training in building and leading teams must be enhanced and an organizational culture that fosters teamwork must be developed.

Coordinated care will be achieved only if generalist practices inform patients about the various team members and their roles. Currently, team care in the United States is largely invisible to patients, who neither know all the team members nor understand their roles. Not surprisingly, patients generally rate the communication and clinical skills of nonphysician team members, whom they describe as "not my doctor," lower than those of their physician (51).

Table 2. Potential Members of Generalist Coordination Teams

Core members from the generalist office
Generalist physicians and other clinicians (for example, nurse practitioners and physician assistants)
Office nurses and nurse aides
Office administrative staff
Patients and family members
Nongeneralist clinician members
Non-primary care specialist and subspecialist physicians
Hospitalists
Mental health clinicians
Midwives
Community members
School or workplace supports (such as teachers and special education staff and employee assistance)
Home health care nurses and other workers (including hospice staff)
Community mental health workers
Long-term care facility (for example, skilled-nursing or assisted-living) administrators and staff
Nonpatient, nonfamily laypersons (such as doulas, trained peer coaches, health care advocacy group members, religious and social group leaders and organizations)
Allied health care members
Social workers
Interpreters
Clinical pharmacists
School and employee health services
Physical and occupational therapists
Complementary medicine practitioners

Creating visible team care will require that practices communicate with patients about teams, by telling them who is on the team and making clear the role of each team member (51). Generalist practices must provide specific education about whom the patient should contact for which types of questions or concerns, who is directing care overall, and who is in charge of specific aspects of care.

5. The role of patients and families as active partners in coordination of care needs to be fostered by the health care system, but also better defined.

The optimal treatment team must offer patients and families a role as full members in the coordination process. Patients and families with complex illnesses desire a substantial role in coordination of care (14, 33, 51), and the most widely accepted model of chronic illness care uses informed, activated patients as a measure of success (47). The phrase "nothing about me without me" has been used increasingly as a guiding principle of health care communication (52) and should be kept in mind when building a system of care coordination. However, the convoluted nature of the current health care system makes it difficult for patients and families to lead efforts to coordinate care, and little is known about the best way to integrate them as full

members of the health care team. Their role is likely to vary with the clinical, psychosocial, and community situation. Studies of models of care coordination in practice must find successful strategies for patient and family integration before more specific, useful recommendations can be made.

One potential danger that may result when coordination within the system does not function is that patients may be left to coordinate all of their own care without sufficient professional support. Although generalist physicians may have the most expertise in professional oversight and integration of specialty care, other team members, such as practice nurses or social workers, may be needed to support patients and families in other aspects of coordination of care, such as integrating community services into the treatment plan. Without oversight by team members who are knowledgeable in these areas, fragmentation of care is likely (9, 36, 38). With the recent decrease in the proportion of managed care plans that require "gatekeeping" by primary care physicians as a means of regulating and coordinating specialty care and the ability of patients to self-refer without contacting their primary care physician, coordination with specialists may be made more difficult (53). Systems must be built to promote the oversight function of gatekeeping while maintaining improved access to appropriate care.

6. Generalists should make rational use of information systems to improve communication and access to increasing amounts of knowledge.

Coordinated health care depends on efficient and accurate transfer of information among clinicians and between patients and clinicians. Electronic health record systems have great potential to improve information flow. They can replace paper medical records and provide decision support, order entry, and communication among care team members (54, 55). Reminders generated by these systems can improve outcomes for patients with chronic disease (56–58), but few studies have examined the effects of electronic health records on care coordination. Access by emergency physicians to outpatient electronic records can lead to less intensive testing and lower costs (59, 60), and a sign-out system for residents that was based on electronic records dramatically reduced the risk for adverse events during cross-coverage (61).

Attention to non-computer-related aspects of medical informatics is essential. Team members must understand medical informatics, which involves more than the use of computers (62); it also focuses on the development of processes for efficient transfer of information and on optimizing interactions within the team. Electronic health records can improve communication by making physicians' notes more easily and widely accessible, but electronically generated notes may also be less accurate because of verbatim copying from earlier notes (63). To enhance communication, systems must move beyond simply making notes

available electronically. Analysis of the flow of information needed among team members could help in the redesign of communications processes, so that verbal protocols (64, 65) and use of computers are involved.

Internet-based services, such as Web sites that offer patient-provider interaction, may also support patients in care coordination (66). Although the quality of these services has been uneven (67) and their uptake by consumers has been slow, the role of online communications is likely to increase in the future (68). Because physicians have much higher and more equitable levels of Internet access than do the general public (69, 70) and, especially, socioeconomically disadvantaged groups (71), organizations should use caution in promoting patient self-coordination through the Internet to avoid widening the existing health care disparities.

Use of electronic health records has become a federal policy objective (72), but barriers to their adoption remain particularly challenging and few physicians in the United States are using them (73, 74). Concerns exist about the privacy of electronically available personal health information (75, 76). Privacy regulations contained in the Health Information Portability and Accountability Act are intended to encourage public acceptance of health information technology by regulating the use of personal health information (77). However, the complexity of this act's rules and their interactions with state and local laws have created uncertainty among providers that is likely to delay acceptance of electronic health records (78). Potential financial barriers are even larger: Early adopters of electronic records have made large time investments, and their practices have remained less time-efficient for months or years (79). They may also experience decreased revenues if the success of the system reduces the need for office visits to coordinate care (80). A cost-benefit analysis found that use of electronic health records could save \$1700 to \$28 000 per provider per year, but the savings largely depended on the proportion of capitated patients (81). In the United States, these financial benefits would generally accrue to parties other than the provider (55). In the United Kingdom, Australia, and the Netherlands, electronic records have been more widely adopted, in large measure because of governmental incentives and standardization (55, 73). Without a combination of standardization and some financial incentive for providers, the rate of adoption of electronic records in the United States is likely to remain slow.

CONCLUSIONS

Although clinical scenarios demonstrate the importance of good coordination of care as an essential part of primary care, objective evidence showing its benefits is limited. Definitions and measurement of coordination must be developed, relevant outcome measures selected, and stronger evidence gathered, so that the value of coordinating care can be justified to payors and policymakers. For

generalist practices to succeed as the locus of care coordination, their value as coordinators needs to be recognized and supported by health care systems as well as other clinicians. A team approach in which roles of patients and families, generalist and specialist physicians, and nonphysician staff are explicit is essential to achieve well-coordinated care. Education of generalist and specialist physicians about communication and collaboration must be an essential part of clinical training so that they may become effective team members and leaders. Medical informatics, which should play an important role as a supporting tool, will require more than simply making computers a routine part of office practice. Financial and organizational disincentives to adoption of electronic medical records must be overcome.

APPENDIX: CLINICAL VIGNETTES

A Coordinated System of Care, with Positive Outcomes

Ms. W., a patient of Dr. Fine, was due for a routine health maintenance visit and mammography. Dr. Fine's office staff had scheduled the mammography before Ms. W.'s visit, thus avoiding delays. At her visit, a lump in the breast was detected on physical examination. Mammography quickly confirmed that the lump was a matter of concern and that biopsy was indicated.

When the results of mammography became available, Dr. Fine's office scheduled a follow-up visit by using an online open scheduling system that made it easy for Ms. W. to be seen the same day. Ms. W. was reassured both by the process and by Dr. Fine's concern about her well-being and role as her advocate, especially because of her concerns about possible results of the upcoming biopsy.

During the visit, Dr. Fine gave Ms. W. detailed information on available surgeons and coached her on questions or issues she might want to explore. While Ms. W. was in the primary care office, Janet, a practice nurse and care coordinator, arranged for her to have the biopsy done within 1 week by the surgeon she had selected. With Janet's help, Dr. Fine communicated the results of Ms. W.'s examination, laboratory tests, and other pertinent health information to the surgeon's office by fax before her surgical appointment. All of that information was easily accessible from Ms. W.'s electronic medical record.

The biopsy showed early-stage cancer, and this result was sent back to Dr. Fine's office by fax. Ms. W. was able to see Dr. Fine the next day to learn about and discuss her options for treatment. Janet assisted her in finding other patients who had faced similar choices. Ms. W. immediately began plans for treatment, which was completed without delay. During this process, Ms. W. frequently spoke with or e-mailed Dr. Fine, Janet, or Dr. Fine's nurse practitioner. She had no trouble reaching these professionals when she had concerns or questions.

An Uncoordinated System of Care, with Negative Outcomes

Ms. M., a new patient of Dr. Usual, called the physician's office to schedule a routine health maintenance visit. She was told that the first available appointment was in 2 months. At that

visit, her breast examination appeared to be normal, but Dr. Usual noted that Ms. M. was due for screening mammography.

Ms. M. called a mammography facility that was listed in her provider directory and was given an appointment in 6 weeks. One week after undergoing mammography, staff from Dr. Usual's called to say that the findings were abnormal and that Ms. M. should make an appointment with a surgeon for biopsy. The first available appointment with the surgeon was 9 weeks later. By now, Ms. M. was very anxious, and she did not sleep well for weeks.

Finally, Ms. M. had her appointment with the surgeon. He had received no results from Dr. Usual or the imaging center, and Ms. M. waited for an hour while his staff tracked down the results. After receiving them, his office scheduled her for biopsy, for which she had to return on another day. The biopsy showed that Ms. M. had breast cancer, and there was concern that it might have spread to her lymph nodes. She felt terrified, angry, sad, and helpless, but needed to decide what kind of surgery to have. She chose mastectomy.

Before she could have surgery, Ms. M. needed to undergo bone and abdominal scanning to rule out metastases. When she arrived at the hospital for surgery, the results of the scans were missing. The surgery almost had to be postponed because of delays in locating them.

During mastectomy, several lymph nodes that tested positive for cancer were found. This meant that Ms. M. had to see the surgeon, an oncologist, and a radiologist, as well as Dr. Usual, to decide on the next steps. It was difficult for her to get a clear idea of which treatment to pursue, as she heard differing opinions from her physicians and was unsure whose recommendations to follow. At last it was decided that she would have radiation therapy and chemotherapy. She was given the telephone number for the American Cancer Society for more information.

The clinical vignettes were adapted with permission from *Crossing the Quality Chasm: A New Health System for the 21st Century*, copyright 2001 by the National Academy of Sciences. Washington, DC: National Academies Pr; 2001.

From University of Massachusetts Medical School, Worcester, Massachusetts; University of California, Davis, Sacramento, and University of California, Los Angeles, Los Angeles, California; University of Chicago, Chicago, Illinois; and University of Washington, Seattle, Washington.

Acknowledgments: The authors thank Kurt Stange, MD, PhD; Richard Wasserman, MD, MPH; and Kenneth Roberts, MD, for thoughtful advice and review of early drafts of the manuscript.

Grant Support: In part by the Robert Wood Johnson Foundation Generalist Faculty Scholars Program (grant 42206) and the National Center for Research Resources (grant G12 RR 03026-13).

Potential Financial Conflicts of Interest: None disclosed.

Corresponding Author: Christopher Stille, MD, MPH, Division of General Pediatrics, University of Massachusetts, Benedict A3-125, 55 Lake Avenue North, Worcester, MA 01655; e-mail, stillec@ummhc.org.

Current author addresses are available at www.annals.org.

References

1. Definitions. Hyperdictionary. Accessed at www.hyperdictionary.com on 8 April 2004.
2. Starfield B. Primary care: Balancing Health Needs, Services, and Technology. New York: Oxford Univ Pr; 1998.
3. Meltzer D. Hospitalists and the doctor-patient relationship. *Journal of Legal Studies*. 2001;30:589-606.
4. Society of General Internal Medicine. Task Force on the Future of General Internal Medicine. Future of general internal medicine: report and recommendations. Accessed at www.sгим.org/futureofGIMreport.cfm on 17 June 2004.
5. ACGME Residency training requirements for Family Medicine and Pediatrics. Accessed at www.acgme.org/acWebsite/navPages/nav_comPR.asp on 10 June 2004.
6. Ziring PR, Brazdziunas D, Cooley WC, Kastner TA, Kummer ME, Gonzalez de Pijem L, et al. American Academy of Pediatrics. Committee on Children With Disabilities. Care coordination: integrating health and related systems of care for children with special health care needs. *Pediatrics*. 1999;104:978-81. [PMID: 10506246]
7. The medical home. *Pediatrics*. 2002;110:184-6. [PMID: 12093969].
8. Grumbach K. Chronic illness, comorbidities, and the need for medical generalism [Editorial]. *Ann Fam Med*. 2003;1:4-7. [PMID: 15043173]
9. Committee on Quality of Health Care in America, Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Pr; 2001.
10. Kisker CT, Fethke CC, Tannous R. Shared management of children with cancer. *Arch Pediatr Adolesc Med*. 1997;151:1008-13. [PMID: 9343011]
11. Schillinger D, Bibbins-Domingo K, Vranizan K, Bacchetti P, Luce JM, Bindman AB. Effects of primary care coordination on public hospital patients. *J Gen Intern Med*. 2000;15:329-36. [PMID: 10840268]
12. Addington-Hall JM, MacDonald LD, Anderson HR, Chamberlain J, Freeling P, Bland JM, et al. Randomised controlled trial of effects of coordinating care for terminally ill cancer patients. *BMJ*. 1992;305:1317-22. [PMID: 1483075]
13. Weinberger M, Kirkman MS, Samsa GP, Shortliffe EA, Landsman PB, Cowper PA, et al. A nurse-coordinated intervention for primary care patients with non-insulin-dependent diabetes mellitus: impact on glycemic control and health-related quality of life. *J Gen Intern Med*. 1995;10:59-66. [PMID: 7730940]
14. Unutzer J, Katon W, Callahan CM, Williams JW Jr, Hunkeler E, Harpole L, et al. Collaborative care management of late-life depression in the primary care setting: a randomized controlled trial. *JAMA*. 2002;288:2836-45. [PMID: 12472325]
15. Palfrey JS, Sofis LA, Davidson EJ, Liu J, Freeman L, Ganz ML, et al. The Pediatric Alliance for Coordinated Care: evaluation of a medical home model. *Pediatrics*. 2004;113:1507-16. [PMID: 15121919]
16. Katon W, Russo J, Von Korff M, Lin E, Simon G, Bush T, et al. Long-term effects of a collaborative care intervention in persistently depressed primary care patients. *J Gen Intern Med*. 2002;17:741-8. [PMID: 12390549]
17. Katon W, Von Korff M, Lin E, Simon G, Walker E, Unutzer J, et al. Stepped collaborative care for primary care patients with persistent symptoms of depression: a randomized trial. *Arch Gen Psychiatry*. 1999;56:1109-15. [PMID: 10591288]
18. Katon W, Von Korff M, Lin E, Walker E, Simon GE, Bush T, et al. Collaborative management to achieve treatment guidelines. Impact on depression in primary care. *JAMA*. 1995;273:1026-31. [PMID: 7897786]
19. Starfield B, Lemke KW, Bernhardt T, Foldes SS, Forrest CB, Weiner JP. Comorbidity: implications for the importance of primary care in 'case' management. *Ann Fam Med*. 2003;1:8-14. [PMID: 15043174]
20. Stange KC. The paradox of the parts and the whole in understanding and improving general practice [Editorial]. *Int J Qual Health Care*. 2002;14:267-8. [PMID: 12201184]
21. Perrin EC, Lewkowicz C, Young MH. Shared vision: concordance among fathers, mothers, and pediatricians about unmet needs of children with chronic health conditions. *Pediatrics*. 2000;105:277-85. [PMID: 10617736]
22. Stott NC. Personal care and teamwork: implications for the general practice-based primary health care team. *Journal of Interprofessional Care*. 1995;9:95-9.
23. Cooley WC. Responding to the developmental consequences of genetic conditions: the importance of pediatric primary care. *Am J Med Genet*. 1999;89:75-80. [PMID: 10559761]
24. McInerney T. The role of the general pediatrician in coordinating the care of children with chronic illness. *Pediatr Clin North Am*. 1984;31:199-209. [PMID: 6701024]
25. Antonelli R, Peer M. Providing a medical home: the cost of care coordination services in a community-based, general pediatric practice [Abstract]. *Pediatr Res*. 2002;51:216A.
26. Hoffman C, Rice D, Sung HY. Persons with chronic conditions. Their prevalence and costs. *JAMA*. 1996;276:1473-9. [PMID: 8903258]
27. Stein RE, Silver EJ. Operationalizing a conceptually based noncategorical definition: a first look at US children with chronic conditions. *Arch Pediatr Adolesc Med*. 1999;153:68-74. [PMID: 9895002]
28. Harrold LR, Field TS, Gurwitz JH. Knowledge, patterns of care, and outcomes of care for generalists and specialists. *J Gen Intern Med*. 1999;14:499-511. [PMID: 10491236]
29. Ayanian JZ, Landrum MB, Guadagnoli E, Gacione P. Specialty of ambulatory care physicians and mortality among elderly patients after myocardial infarction. *N Engl J Med*. 2002;347:1678-86. [PMID: 12444183]
30. Christakis DA, Feudtner C, Pihoker C, Connell FA. Continuity and quality of care for children with diabetes who are covered by medicaid. *Ambul Pediatr*. 2001;1:99-103. [PMID: 11888380]
31. Starfield B. Primary care. Participants or gatekeepers? *Diabetes Care*. 1994;17 Suppl 1:12-7. [PMID: 7980836]
32. Greenfield S. The next generation of research in provider optimization [Editorial]. *J Gen Intern Med*. 1999;14:516-7. [PMID: 10491239]
33. Miller MR, Forrest CB, Kan JS. Parental preferences for primary and specialty care collaboration in the management of teenagers with congenital heart disease. *Pediatrics*. 2000;106:264-9. [PMID: 10920149]
34. Nash DB, Nash IS. Building the best team [Editorial]. *Ann Intern Med*. 1997;127:72-4. [PMID: 9214256]
35. Young PC, Shyr Y, Schork MA. The role of the primary care physician in the care of children with serious heart disease. *Pediatrics*. 1994;94:284-90. [PMID: 8065851]
36. Palfrey JS, Levy JC, Gilbert KL. Use of primary care facilities by patients attending specialty clinics. *Pediatrics*. 1980;65:567-72. [PMID: 7360546]
37. Kanthor H, Pless B, Satterwhite B, Myers G. Areas of responsibility in the health care of multiply handicapped children. *Pediatrics*. 1974;54:779-85. [PMID: 4279390]
38. Epstein RM. Communication between primary care physicians and consultants. *Arch Fam Med*. 1995;4:403-9. [PMID: 7742962]
39. McPhee SJ, Lo B, Saika GY, Meltzer R. How good is communication between primary care physicians and subspecialty consultants? *Arch Intern Med*. 1984;144:1265-8. [PMID: 6732382]
40. Byrd JC, Moskowitz MA. Outpatient consultation: interaction between the general internist and the specialist. *J Gen Intern Med*. 1987;2:93-8. [PMID: 3550011]
41. Cummins RO, Smith RW, Inui TS. Communication failure in primary care. Failure of consultants to provide follow-up information. *JAMA*. 1980;243:1650-2. [PMID: 7359754]
42. Gandhi TK, Sittig DF, Franklin M, Sussman AJ, Fairchild DG, Bates DW. Communication breakdown in the outpatient referral process. *J Gen Intern Med*. 2000;15:626-31. [PMID: 11029676]
43. Forrest CB, Glade GB, Baker AE, Bocian A, von Schrader S, Starfield B. Coordination of specialty referrals and physician satisfaction with referral care. *Arch Pediatr Adolesc Med*. 2000;154:499-506. [PMID: 10807303]
44. Stille CJ, Primack WA, Savageau JA. Generalist-subspecialist communication for children with chronic conditions: a regional physician survey. *Pediatrics*. 2003;112:1314-20. [PMID: 14654603]
45. Newton J, Eccles M, Hutchinson A. Communication between general practitioners and consultants: what should their letters contain? *BMJ*. 1992;304:821-4. [PMID: 1392712]
46. Rothman AA, Wagner EH. Chronic illness management: what is the role of

- primary care? *Ann Intern Med.* 2003;138:256-61. [PMID: 12558376]
47. **Bodenheimer T, Wagner EH, Grumbach K.** Improving primary care for patients with chronic illness. *JAMA.* 2002;288:1775-9. [PMID: 12365965]
48. **The future of pediatric education II.** Organizing pediatric education to meet the needs of infants, children, adolescents, and young adults in the 21st century. A collaborative project of the pediatric community. Task Force on the Future of Pediatric Education. *Pediatrics.* 2000 Jan;105(1 Pt 2):157-212. [PMID: 10647117]
49. **Grumbach K, Bodenheimer T.** Can health care teams improve primary care practice? *JAMA.* 2004;291:1246-51. [PMID: 15010447]
50. **Stott NC.** William Pickles Lecture 1993. When something is good, more of the same is not always better. *Br J Gen Pract.* 1993;43:254-8. [PMID: 8373650]
51. **Safran DG.** Defining the future of primary care: what can we learn from patients? *Ann Intern Med.* 2003;138:248-55. [PMID: 12558375]
52. **Delbanco T, Berwick DM, Boufford JI, Edgman-Levitan S, Ollenschläger G, Plamping D, et al.** Healthcare in a land called PeoplePower: nothing about me without me. *Health Expect.* 2001;4:144-50. [PMID: 11493320]
53. **Forrest CB, Glade GB, Starfield B, Baker AE, Kang M, Reid RJ.** Gatekeeping and referral of children and adolescents to specialty care. *Pediatrics.* 1999;104:28-34. [PMID: 10390256]
54. **Institute of Medicine.** Key Capabilities of an Electronic Health Record System. Washington, DC: National Academies Pr; 2003.
55. **Bates DW, Ebell M, Godlieb E, Zapp J, Mullins HC.** A proposal for electronic medical records in U.S. primary care. *J Am Med Inform Assoc.* 2003; 10:1-10. [PMID: 12509352]
56. **Jerant AF, Hill DB.** Does the use of electronic medical records improve surrogate patient outcomes in outpatient settings? *J Fam Pract.* 2000;49:349-57. [PMID: 10778842]
57. **Mitchell E, Sullivan F.** A descriptive feast but an evaluative famine: systematic review of published articles on primary care computing during 1980-97. *BMJ.* 2001;322:279-82. [PMID: 11157532]
58. **Weiner M, Callahan CM, Tierney WM, Overhage JM, Mamlin B, Dexter PR, et al.** Using information technology to improve the health care of older adults. *Ann Intern Med.* 2003;139:430-6. [PMID: 12965971]
59. **Wilson GA, McDonald CJ, McCabe GP Jr.** The effect of immediate access to a computerized medical record on physician test ordering: a controlled clinical trial in the emergency room. *Am J Public Health.* 1982;72:698-702. [PMID: 7046482]
60. **Overhage JM, Dexter PR, Perkins SM, Cordell WH, McGoff J, McGrath R, et al.** A randomized, controlled trial of clinical information shared from another institution. *Ann Emerg Med.* 2002;39:14-23. [PMID: 11782726]
61. **Petersen LA, Orav EJ, Teich JM, O'Neil AC, Brennan TA.** Using a computerized sign-out program to improve continuity of inpatient care and prevent adverse events. *Jt Comm J Qual Improv.* 1998;24:77-87. [PMID: 9547682]
62. **Shortliffe EH.** Medical informatics meets medical education. *JAMA.* 1995; 273:1061, 1064-5.
63. **Embi PJ, Yackel TR, Logan JR, Bowen JL, Cooney TG, Gorman PN.** Impacts of computerized physician documentation in a teaching hospital: perceptions of faculty and resident physicians. *J Am Med Inform Assoc.* 2004;11:300-9. [PMID: 15064287]
64. **Parker J, Coiera E.** Improving clinical communication: a view from psychology. *J Am Med Inform Assoc.* 2000;7:453-61. [PMID: 10984464]
65. **Coiera E.** When conversation is better than computation. *J Am Med Inform Assoc.* 2000;7:277-86. [PMID: 10833164]
66. **Goldsmith J.** How will the Internet change our health system? *Health Aff (Millwood).* 2000;19:148-56. [PMID: 10645081]
67. **Kim MI, Johnson KB.** Personal health records: evaluation of functionality and utility. *J Am Med Inform Assoc.* 2002;9:171-80. [PMID: 11861632]
68. **Katz SJ, Moyer CA.** The emerging role of online communication between patients and their providers. *J Gen Intern Med.* 2004;19:978-83. [PMID: 15333064]
69. **Casebeer L, Bennett N, Kristofco R, Carillo A, Centor R.** Physician Internet medical information seeking and on-line continuing education use patterns. *J Contin Educ Health Prof.* 2002;22:33-42. [PMID: 12004639]
70. **Bell DS, Daly DM, Robinson P.** Is there a digital divide among physicians? A geographic analysis of information technology in Southern California physician offices. *J Am Med Inform Assoc.* 2003;10:484-93. [PMID: 12807804]
71. **Levy KK, Price L, McConnaughey J, Buckley P, Lader W, Montes S, et al.** A nation online: how Americans are expanding their use of the internet. Washington, DC: U.S. Department of Commerce; 2002. Accessed at www.ntia.doc.gov/ntiahome/dn/index.html on 17 June 2004.
72. **The decade of health information technology: delivering consumer-centric and information-rich health care.** U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology. Accessed at www.hhs.gov/healthit/documents/hitframework.pdf on 1 September 2004.
73. **Brailer DJ, Terasawa EL.** Use and adoption of computer-based patient records. Accessed at www.chcf.org/documents/ihealth/UseAdoptionComputerizedPatientRecords.pdf on 1 September 2004.
74. **Reed MC, Grossman JM.** Limited information technology for patient care in physician offices. Washington, DC: Center for Health System Change; 2004.
75. **Gostin LO, Turek-Brezina J, Powers M, Kozloff R, Faden R, Steinauer DD.** Privacy and security of personal information in a new health care system. *JAMA.* 1993;270:2487-93. [PMID: 8192748]
76. **Health privacy polling data.** The Health Privacy Project. Accessed at www.healthprivacy.org/usr_doc/polling_data.pdf on 26 October 2004.
77. **Standards for privacy of individually identifiable health information.** Office of the Assistant Secretary for Planning and Evaluation, DHHS. Final rule. *Fed Regist.* 2000 Dec 28;65(250):82462-829. [PMID: 11503738]
78. **Greenberg MD, Ridgely MS, Bell DS.** Electronic prescribing and HIPAA privacy regulation. *Inquiry.* [In press].
79. **Miller RH, Sim I.** Physicians' use of electronic medical records: barriers and solutions. *Health Aff (Millwood).* 2004;23:116-26. [PMID: 15046136]
80. **Kolata G.** Health plan that cuts costs raises doctors' ire. *The New York Times.* 2004;11 Aug:A17.
81. **Wang SJ, Middleton B, Prosser LA, Bardón CG, Spurr CD, Carchidi PJ, et al.** A cost-benefit analysis of electronic medical records in primary care. *Am J Med.* 2003;114:397-403. [PMID: 12714130]

Current Author Addresses: Dr. Stille: Division of General Pediatrics, University of Massachusetts, Benedict A3-125, 55 Lake Avenue North, Worcester, MA 01655.

Dr. Jerant: Family Medicine, University of California, Davis, School of Medicine, University of California Davis Medical Center, 4860 Y Street, Suite 2300, Sacramento, CA 95817.

Dr. Bell: Division of General Internal Medicine, David Geffen School of Medicine at University of California, Los Angeles, 911 Broxton Plaza, Room 314, Los Angeles. CA 90095-1736.

Dr. Meltzer: General Internal Medicine, Department of Economics, University of Chicago, 5841 South Maryland, MC 207, B220, Chicago, IL 60637.

Dr. Elmore: General Internal Medicine, Harborview Medical Center, Mailbox 359780, 325 Ninth Avenue, Room 10EH03, Seattle, WA 98104.