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Ambiguities of chronic illness management and challenges to the medical error paradigm

Karen E. Lutfey^{a,*}, Jeremy Freese^b

^aNew England Research Institutes, Watertown, MA, USA

^bRobert Wood Johnson Foundation Scholars in Health Policy Research Program, Harvard University and Department of Sociology, University of Wisconsin-Madison, USA

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Abstract

In recent decades, an interdisciplinary quality assurance (QA) movement has emerged in health care studies, which has included increased attention to medical errors. Implicit in this QA effort is a conflict between (1) external agents encouraging the medical profession to adopt strategies for reducing errors and (2) sociological characteristics of medical practice that systematically inhibit the uptake of these strategies. Using interviews with providers and observations in two diabetes clinics in a large Midwestern city in the USA, we examine how providers understand error in their work, as well as how they think about failures in care and efforts to standardize and impose guidelines in care. We find that the prototypical vocabularies of medical error and QA, which have been largely oriented to acute illness care, are systematically mismatched to ambiguities introduced by chronic illness. These ambiguities create problems for the definition of medical errors, the collection of relevant information, the determination of long-term treatment goals, and the application of standardization efforts. Considered together, these mismatches imply diminishing returns for health policy efforts focused on reducing medical error as part of a larger QA agenda. © 2006 Elsevier Ltd. All rights reserved.

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Introduction

Over the course of several decades, efforts to improve quality of health care provision have developed into a massive, interdisciplinary undertaking that seeks to identify potential weaknesses in medical care and minimize their economic, social, and outcome-related effects. The IOM report *Crossing the Quality Chasm* (2001, p. 41–53) identifies six pillars of quality care—safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity—and suggests that the US should strive for improvement on each of these fronts. One segment of this agenda that has become increasingly prominent in recent years has been the study of medical errors, precipitated in part by the Harvard Medical Practice Study (Leape et al., 1991), the Utah–Colorado Medical Practice Study (Thomas et al., 2000), and especially the 2000 Institute of Medicine (IOM) report, *To Err is Human*.

These efforts to increase quality coincide with an increased prevalence of chronic (as opposed to acute) illness in the US, and this intersection is the focus of our paper. Specifically, we focus on

^{*}Corresponding author. Tel.: +16179237747.

E-mail addresses: klutfey@neriscience.com (K.E. Lutfey), jfreese@rwj.harvard.edu (J. Freese).

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questions related to the everyday practicalities of medical work in two diabetes clinics, and how the potential for mistakes in practice is conceptualized. executed, and accounted for by providers. Using interviews with providers and observation in clinics, we examine how providers understand error in their work and how they think about failures in care and efforts to standardize and impose guidelines in care. We find that the prototypical vocabularies of medical error and quality assurance (QA) are systematically mismatched to the work of diabetes care. Chronic illness introduces ambiguities on many of the very fronts that have been useful for consideration of both errors specifically and quality improvement more generally in acute care settings, and we articulate several such ambiguities in our analysis below. The implication for policy is that QA efforts, especially those surrounding the notion of medical error, seem likely to face diminishing returns in the context of ambulatory chronic illness management. Our results reinforce longstanding calls for a more systems-oriented approach to chronic illness care (Bodenheimer, Wagner, & Grumbach, 2002).

Mistaken practice in medical care

To Err is Human defines "medical error" as "the failure of a planned action to be completed as intended (i.e., error of execution) or the use of a wrong plan to achieve an aim (i.e., error of planning)" (Institute of Medicine, 2000, p. 28). When an injury is caused by medical management, rather than by the underlying condition of a patient, a "preventable adverse event" is said to have occurred. The report's definitions of medical error and preventable adverse events clearly center on the acute hospital care setting. Indeed, in reviewing the literature on medical error from which it draws, the report notes that "little if any research has focused on errors or adverse events occurring outside of hospital settings" (Institute of Medicine, 2000, p. 29). Similarly, media attention to the topic of medical error seems to focus exclusively on the acute care setting, highlighting surgical mistakes and errors in types and dosages of medications given to hospitalized patients.

At the same time, a long tradition of sociological research has focused on documenting various aspects of the nature of medical work. Here, much attention has been allocated to the uncertainty and risk inherent in medical work, how providers are socialized to manage such uncertainty, and the role of professional collegiality and internal social control in managing the risks associated with uncertainty (Bosk, 1979; Fox, 1957; Light, 1972; Sharpe & Fadin, 1998). Researchers have called attention to the inevitable nature of medical mistakes (Millman, 1977), claiming that "mistakes are an indigenous feature of the work process as it unfolds" (Paget, 1988).

On one level, this work reflects sentiments similar to those emphasized in the IOM report on errors: even the most highly trained human actors are inevitably prone to occasional lapses in practice, and this inescapable propensity is often best addressed by changing aspects of the system to make patients less vulnerable to provider lapses. However, sociological work goes beyond this observation to suggest that uncertainty is ongoing, inherent, and inescapable in medical practice, and mistakes that are tied to this uncertainty cannot readily be separated from the work itself. Even with a system designed to provide system safeguards against mistakes such as dosage errors or lab miscommunications, the basic work of treating illness involves many things that cannot be known in advance (Light, 1972; Paget, 1988; Pope, 2002). Human error, at least in the broader sense of actions that come to be understood as mistaken, is more than inevitable; it is bound up in the nature of the work.

Especially in its focus on patient safety, much discussion of medical "error" has focused mainly on readily identifiable lapses that suggest moments of incompetence or negligence. Beyond this, however, the routine uncertainty of medical work can create conditions in which mistakes in retrospect (actions which only become evident as mistakes because of an adverse consequence) become difficult to distinguish from mistakes in prospect (actions which could have been identified as mistaken at the outset and for which adverse events would seem more justifiably deemed "preventable"). While we recognize that medical error per se has been treated as one distinct facet of a larger QA agenda, physicians in our data point to several aspects of their work wherein the distinction between the two types of mistakes is unclear, such that events that would count as "errors" in acute care are largely absent in chronic care, while decisions, events, and outcomes typically attributed to patient non-compliance or to clinical ineffectiveness in acute care may actually be interpreted as an issue of mistaken practice in chronic care.

The sociological research would lead us to expect there to be difficulties and contestation in identifying medical activities as "errors" across all types of care, not just in the more ambiguous territory of chronic illness management on which we focus. Indeed, such difficulties appear common in studies of medical error. While much public attention has been captured by assertions that as many as 98,000 patients a year are killed by preventable errors in acute hospital care (IOM, 2000), significant debates have emerged over whether the IOM and other estimates are inflated (e.g., McDonald, Weiner, & Hui, 2000). Hayward and Hofer (2001, p. 419), for example, emphasize that study results suggest that even expert reviewers have much difficulty agreeing in particular instances about whether an error has occurred and whether it caused an adverse event that would have otherwise been prevented. We are agnostic to the merits of either side of this debate, but instead wish only to point out that the debate's existence illustrates that the identification of error is readily contested even in settings where we might assume that policy is most aptly positioned to guide actual work.

Our own study considers the identification of mistakes in practice in the quite different context of chronic illness management. Although the distinction has obvious limitations, acute care may be often characterized by patients having passive roles in the process; their families and social support networks being less active; and long-term patientprovider relationships having less impact on treatment outcomes. Indeed, for providers, acute treatment may often even entail a one-time assessment of patients, as well as a one-time determination of treatment goals and strategies. By contrast, the chronic care end of the spectrum is characterized by patients having active roles in self-management, along with expanded involvement of families and other members of social support networks in ongoing treatment. The patient-provider relationship also becomes more critical over time, as iterative, and often collaborative, treatment plans unfold. While acute complications certainly arise in diabetes care, much ongoing care exemplifies the chronic end of this continuum, as we describe further below. For these reasons, our study focuses on diabetes care as a possibly useful site for articulating the special issues that chronic illness management may raise for quality improvement efforts.

The case of diabetes

Diabetes provides an exemplary case for studying many dimensions of chronic illness management: it is a disease that is controlled rather than cured; medical interventions are strategized iteratively and in response to a wide array of physiologic, psychological, and social responses; and outcomes unfold over extended periods of time, generally years. Patients play a critical role in successful diabetes management, as they are expected to independently manage complex daily treatment regimens involving medication, diet, and exercise in order to avoid the long-term complications that accompany high glucose, such as circulatory precursors to amputation, blindness, kidney failure, heart disease, and stroke. Diabetes regimens become more complex with the addition of multiple insulin injections (or even insulin pumps); mixing of longand short-acting insulins; more extensive monitoring and assessing of food content; adjusting dosages of insulin according to algorithms; and increased glucose monitoring.

Standardization and guidelines have played a central role in discussions of both QA and medical errors, building on the assumption that standardization will help improve quality (Rozich et al., 2004). Table 1 below summarizes one major set of outcome recommendations for diabetes care (American Diabetes Association, 2006). First are measures of *outcomes* designed to minimize the likelihood that patients will experience the long-term complications associated with chronically elevated glucose levels, including several measures of glucose control, blood pressure, and lipids.

Of course, a key question in thinking about quality of care and chronic illness is the processes by which patients achieve these outcomes, and guidelines are intended to infuse some standardization into this aspect of care as well. The text portion of these guidelines describes a "comprehensive diabetes evaluation" as including a medical history, physician examination, laboratory evaluation, and referrals for complications screening (i.e., eyes, feet, kidneys) (ADA, 2006, p. S9). A management plan should involve several people, forming "an individualized therapeutic alliance among the patient and family, the physician, and other members of the health care team" (pp. S9). Furthermore, guidelines acknowledge that not all patients can accomplish the same level of glucose control, and so variables such as age, comorbidities, social situations, cultural

Table 1 Standards of medical care for patients with diabetes mellitus^a

Glycemic control Hemoglobin HbA1c	<7.0%
Preprandial glucose	90-130 mg/dl
Peak Postprandial glucose	<180 mg/dl
Blood pressure	130/80 mmHg
Lipids	
LDL	<100 mg/dl
Triglycerides	<150 mg/dl
HDL	> 40 mg/dl
Key concepts in setting glycemic goals:	
• HbA1c is the primary target for glycemic control	

- Goals should be individualized
- Certain populations (children, pregnant women, and elderly) require special considerations
- More stringent glycemic goals (i.e., a normal HbA1c <6%) may further reduce complications at the cost of increased risk of hypoglycemia
- Less intensive glycemic goals maybe indicated in patients with severe or frequent hypoglycemia
- Postprandial glucose may be targeted if HbAlc goals are not met despite reaching preprandial glucose goals

^aAdapted from American Diabetes Association, 2006. "Standards of Medical Care in Diabetes—2006." *Diabetes Care* 29 (Suppl. 1), S4–42, Table 6.

factors, and psychosocial status should be considered when developing a self-management plan (pp. S9 and S16). While these guidelines provide some signposts for standardizing a highly complex and individualized treatment process, our data suggest critical gaps between these specifications and the actual work that diabetes providers do.

Data and methods

Data are from an ethnographic and interview data collection conducted by the first author in 1997-1998 and 2004. The fieldwork sites were two weekly subspecialty endocrinology clinics at two hospitals that are both part of the same Universitybased medical center located in a large, Midwestern city in the USA. The clinics, Park and County, were selected to provide an optimal contrast of the socioeconomic diversity of persons with diabetes. Patient surveys indicate that those at County clinic are less likely to be white, are more likely to be uninsured, and have lower incomes and education than patients at Park clinic (see Table 2). The organization of personnel also differs between the two clinics. Park relies heavily on two endocrinologists with regular patient caseloads; makes relatively light use of residents; and has a formal diabetes education center with various full- and part-time staff. By contrast, County clinic has several attending physicians (including physicians from a nearby pharmaceutical company who attend clinics periodically), but relies heavily on endocrinology fellows and residents, and depends upon an ad hoc staff of nurses and educators for diabetes education.

The current analysis draws primarily from semistructured telephone interviews conducted with providers in 2004, but also draws from extensive ethnographic data collected from the same clinics in 1997–1998, including clinic observations, in-depth interviews with providers, videotaped patient-provider interactions, focus groups, and telephone surveys with patients (see Lutfey & Freese, 2005 for details). Interviews in 2004 consisted of 8-10 questions, and were piloted with the three physicians who were most heavily involved in the 1997-1998 data collection. Interviews were completed with close to a census of all the providers seeing diabetes patients in these clinics (N = 21), including faculty physicians, research physicians from a neighboring pharmaceutical company who spent 15% of their time in clinic, endocrinology fellows, nurses, and diabetes educators (Table 3). Three respondents who had relocated to different parts of the system since 1997-1998 were also re-interviewed.

Interview questions focused on providers' decision-making in chronic illness management; the

Table 2
Clinic population characteristics (1997–1998 Patient Telephone Survey, $N = 170$) ^a

Clinic population characteristics		County clinic	<i>p</i> -value	
Black/Hispanic (%)	12	45	<.001	
Mean family income	\$56,000	\$12,000	<.001	
Family income \$15,000 or less (%)	12	75	<.001	
Without health insurance (%)	3	42	<.001	
College graduates (%)	41	9	<.001	
Less than high school education (%)	11	36	<.001	
Patient self-assessments of health (0-0 self-rating), 10 is most healthy (mean)	6.80	5.59	<.001 ^b	
Physician assessments of diabetes control (0–10 self-rating), 10 is best controlled (mean)	6.63	4.91	<.001 ^b	
N	137	33		

^aSince 1998, this research center has opened another subspecialty clinic located in the suburbs of the metropolitan area in which they are located ("Northern" in Table 3). While this clinic is designed to serve a population relatively similar to that of Park, we do not have data concerning the patient characteristics of that setting.

^b*p*-values based on non-parametric (Mann–Whitney) test.

Table 3	
Provider population interviewed in	2004

Sex	Education ^a	Occupation	Clinics ^b	1997-1998 participant?	Years in University system
F	MD	University faculty research physician	U, N	Y	10
Μ	MD	Pharmaceutical research physician	С	Y	5
Μ	PhD	University faculty researcher	N/A	Y	15
Μ	MD	Pharmaceutical research physician	C	Y	12
F	RD/CDE	University Diabetes Center	U	Ν	4
Μ	MD	University faculty research physician	U, C, N	Y	15
Μ	MD	University faculty research physician	U, C, N	Ν	5
Μ	MD	University faculty research physician	U, C, N	Y	10
F	RN/CDE	University in-patient protocol developer	U	Y	24
Μ	MD/PhD	University faculty research physician	VA	Y	9
Μ	MD	University faculty research physician	U, C, N	Y	6
F	RN/CDE	University Diabetes Center	U	Y	8
Μ	MD	University faculty research physician	Retired (U, C)	Y	27
Μ	MD	University faculty research physician	Retired (U, C)	Y	51
F	RN/PhD	VA diabetes nurse practitioner	VA	Y	16
Μ	MD	University faculty research physician	U, N	Ν	28
Μ	MD	University faculty research physician	U, C	Ν	4
Μ	MD	University faculty research physician	Internal med.	Ν	3
F	RD/CDE	University insulin pump director	U, CH	Ν	6
F	MD	County endocrine fellow	C	Ν	2
Μ	MD	County endocrine fellow	С	Ν	2

^aRD-Registered dietitian; CDE-Certified diabetes educator; RN-Registered nurse.

^bClinic codes: U—University, C—County, N—Northern, VA—Veterans' Administration, CH—Children's Hospital.

ways they make sense of outcomes that differ from their expectations; and how they distinguish between "errors" and the expected modification of treatment plans over time. Interviews were transcribed by a professional transcriber specializing in academic research. Using a grounded theory approach, we used the qualitative software analysis program Atlas.ti to identify and assign emergent codes to interviewer responses that could then be used to identify recurrent themes and opinions articulated by providers (Glaser & Strauss, 1967).

The ambiguity of adverse events

In the acute care setting, preventable adverse events allow the possible identification of errors in the processes that caused them. For the providers we interviewed, the most readily cited examples of possible errors in chronic care followed closely on the acute care prototype. Some used the phrase "true error" to characterize violations of prescribed, standardized actions that are objective and readily identifiable, with medication errors providing the most salient and frequently offered example:

A true error is using contraindicated meds, using inappropriate regimens that are—(for example) someone needs a touch of insulin and you give them 100 (units), you give them twice the amount that they need on a daily basis. Anybody could look at it for two seconds and figure that out.

Medication errors provide unambiguous examples of error because recommended practices may be readily quantified and articulated, and the consequences of lapses from those practices can often be immediate and severe adverse events. Providers regarded themselves as accountable to guidelines about contraindications and algorithms for dosage of medications, and they also pointed to the importance of surveillance from nurses, pharmacists, and other providers in safeguarding against possible lapses.

When the interviews moved beyond simple examples like medication errors, providers exhibited much more hesitancy and dissensus in talking about the possibility of error in their work. One key problem seemed that "preventable adverse events" provide a much less useful point of departure for talking about error in the everyday clinical situations providers face in diabetes care. Much work of diabetes care is focused on attempting to prevent or postpone adverse events that unfold over a prolonged illness career. Often, patients will present elevated glucose levels for years, then followed by the gradual but insidious development of complications related to eye, kidney, nerve, or vascular functioning. The outcomes are thus more adverse "developments" than discrete adverse "events." Consequences occur much later than any ineffective treatment planning involved in their occurrence. The relationship between glucose levels and diabetes complications is also intrinsically probabilistic, rendering the relationship between given treatment decisions and outcome even more unclear. As such, a provider does not "cause" a stroke by overseeing a treatment plan of chronically high glucose in the same way that a surgeon "causes" the amputation of the wrong leg.

Indeed, while prototypical preventable adverse events refer to *injuries* caused by medical management rather than the underlying condition of a patient, the majority of diabetes sequelae are caused in a proximal sense by the progression of the disease. Therefore, even in cases where patients experience a clearly defined medical event, such as a stroke or heart attack, that outcome is more readily interpreted as the result of the underlying condition of diabetes rather than being caused by medical mismanagement. As described by one provider:

Many times, [error] is subjective. If you ask a person that has done it, he or she will always say, "It's a change in the course of the illness, or there's another problem, I didn't make an error." If you have an objective person review the chart, review the case, review the patient, the physical findings, you may find just the opposite.

Even when adverse events can be said to be "preventable" if the disease had been managed better, that failure is the absence of effective intervention where intervention was possible, rather than the presence of identifiable injurious action. In this way, the prototypical vocabulary of preventable adverse events is systematically mismatched to the work of diabetes management. Much work involves subjective and provisional judgments whose evaluation in terms of "preventable adverse events" is both less possible and less useful.

Uncertainty and iterative treatment planning

Mistaken practice is easier to talk about the clearer it is what providers "should" do, and such clarity increases to the extent providers have complete relevant information. The situation that characterizes provider decision-making in routine diabetes care, however, is often deeply information impoverished. As one physician describes it:

I almost wish I had one of those devices that Mr. Spock had... a little device that he put over the patient, and it told him what was going on.... [Y]ou're looking at a very complex series of data, scratching your head, and you wish you had kind of a device that would allow you to immediately know what the right answer is. *It's clear in retrospect, but when you're proactively trying to make decisions based on a little amount of data, it's very complicated.*

In pining for this science-fiction device, the provider might actually understate the deficiencies of the information environment. For the problem is not just one of information about the biological system that is presenting as a patient, but of the psychology and social circumstances of a person charged with implementing treatment recommendations amidst all the other demands of their lives.

Providers pointed to the difficulty of judging actions as errors given the complexities that incomplete and changing patient information implies for the character of the work:

[T]he majority of the time, it's just trying to understand a very complex system that has a phenomenal number of variables, and you're tweaking one or two.

Each time a patient comes to clinic, a provider is faced with a decision about whether or how to modify a treatment plan. Such treatment plans are not directed toward the unambiguous goal of a "cured" patient, but instead are directed toward making the best of an ongoing and open-ended illness. As such, in diabetes care, there is no single correct treatment, but instead definitions of optimal treatments unfold over time as new information becomes available. Even when a treatment plan is plainly not working and something must be done, the provider may have trouble figuring out why the plan is not working and thus what should be done.

The notion of "tweaking" articulated in the quotation above highlights the ways the providers' work is *iterative*. Tweaking implies trying things out with high uncertainty about whether they will work, which in turn implies the work carries the expectation that some things that are tried will not help the patient and may even have unanticipated adverse consequences. Many of the treatment decisions made in the course of routine clinic visits for diabetes are intendedly provisional, and their subsequent reversal in a return visit carries no implication that they were errors. Indeed, as some providers noted, not trying things could be interpreted as more mistaken.

In acute care settings, practitioner decisions often rely heavily on (and may be accountable to) lab results or information gained from standard questions or checklists. In diabetes care, the truly crucial information for obtaining improved glucose control may be outside the purview of such instruments, as it may concern some aspect of patients' lives that can only be discovered through interaction with the patient. This problem is illustrated in the case of one African-American male patient we saw in County Clinic. When the resident asked about his insulin

regimen, he told her that he never took his afternoon injection. When she presented the case to the attending physician, she reported that the patient was massively "non-compliant" (neither of them had ever seen the patient prior to this visit). Indeed, he brought no log of his glucose tests, and told the resident his tests were usually in the 100-180 range when his Hemoglobin HbA1c indicated an average value of at least 220. The attending physician then proceeded to the exam room with an assumption that the patient's problem was a *psychological* matter of low motivation. After interviewing the patient himself, however, the physician learned that the patient typically worked the graveyard shift as a dishwasher at a restaurant, so he was typically sleeping when he was scheduled to take his afternoon insulin injection. The physician then changed the patients' regimen to work around this circumstance.

An interpretation of the patient's behavior as non-compliant (and therefore resistant to further medical intervention) may have led to an error of undertreatment of his condition. One observation about this example is that the unfolding, iterative nature of chronic treatment facilitates the metamorphosis of "mistakes" into more optimal treatments without ever being oriented to as errors (in this case, it is treated as an educational opportunity for the attending physician to teach the resident about medical interviewing). Errors in this kind of information gathering and interpretation can have injurious consequences, but are much different from "true errors" like misdosing medication, and are also quite distinct from failures to gather the sort of information that may be readily included on a checklist, like questions about drug allergies.

Indeed, in any view of error that focuses on "responsibility," the patient can be judged as responsible for not volunteering this explanation either to the resident or in a previous clinic visit. The IOM distinction between errors of execution and errors of planning becomes complicated in diabetes care because, in regimen design, *it is often the physician who plans and the patient who executes.* The distinction therefore makes it difficult to think about the nature of errors in planning that result from the absence of potentially available information that would improve prospects of successful execution.

The increased likelihood of such complications can be plain from a set of greatly elevated Hemoglobin HbA1c tests over time, but such a profile itself reveals little about the reason for the chronically suboptimal outcomes. Is the nature of the disease and circumstances of treatment such that a chronically elevated profile is really the best that could be done, under the circumstances? If so, how would this determination be made except through the repeated failure to find ways to do something better? The failure to continue to try to improve circumstances might itself reflect an *error of aspira-tion* for the patient—not an error of planning, but an error in the formulation of goals for the patient that inform planning—or it might just reflect a reasonable assessment of what can be achieved.

Responsibility and reduced aspirations

As the preceding suggests, because diabetes cannot be cured, treatment must revolve around managing the disease as well as possible, according to the needs and capacities of individual patients. Throughout the interviews, providers referred to clinical experiences wherein patients were not willing or able to participate in their diabetes management in ways that would allow them to achieve recommended guidelines for glucose levels. As Table 1 indicates, guidelines often provide goals without much information about how those goals might be reached. To assess the feasibility of reaching goals, providers described working like "detectives" with other members of the provider team to try to discover barriers to better adherence and then try to remove them. Since it is a rare patient who can manage tight glucose control, however, most providers described having patients with whom they faced a discrepancy among guideline recommendations, their own personal goals for patients (long- and short-term), and goals articulated or manifested in behavior by those patients. In other words, providers are often put in the position of sanctioning plans of action that are plainly suboptimal in terms of their ability to achieve abstract standards but which match the concrete situation posed by a patient whose execution of regimens upon leaving the clinic is outside the doctor's control.

Some providers did this by giving patients full responsibility for their own goals, as this physician explained when asked whether he revises his treatment goals for patients who do not adhere to prescribed regimens:

I like to refer to it as revising the patient's goals. They're the ones that make the goal. It's kinda

like, if you're trying to learn to play guitar. what's your goal? Do you just want to plink around on it at night and entertain yourself, do you want to play at parties, or do you want to join the Pat Matheny group? I mean, there's different levels of accomplishment that you need to determine, where do you want to go? I try to determine with the patient-here's risks and benefits of optimal glycemic control, and here's what it requires, and understanding all that, where do you see yourself falling? What are you willing to do, and where do you want to go?... It's not my goals. I mean, my goal is for everyone to have a normal A1c. But that's obviously not going to happen, and if I try to take a guy who's not going to do any of the things required and keep beating him over the head because his A1c isn't 5.5, that doesn't do either one of us any good. So my job is to make sure he knows the risks of not controlling his blood sugar.

In this case, the provider protects the integrity of his own, guideline-consistent goals for patient treatment, even though that goal is distinct from that which is pursued in treatment (which is the "patient's goal"). The accountability of the medical system, in this view, is in providing patients with information about how their actions affect their risk of negative outcomes, such that if patients have complications later in life and then wish their adherence had been better, that error is their own. Many other providers described revising their goals away from recommended guidelines in favor of goals that seemed more plausible for specific patients.

Providers did not all see themselves as so passive in whether patients behaved in ways consistent with more demanding regimens. Indeed, one physician described the point as one way providers can err:

You can be overly aggressive, you could not have provided them the skill sets and the environments to be able to use an aggressive insulin regimen without predisposing to hypoglycemia.

That one can be "overly aggressive" again highlights the orientation of treatment planning to figure out the best that can be done under the circumstance. The overly aggressive plan could be taken as an error of planning because it overestimates what the patient can do and so fails by errors of execution. More importantly in this example, however, the provider says that the real failure was not in the plan or the execution but in the provision of the skills or environments to execute the plan properly. Such errors of investment may well be attributable to the provider, especially if the provider "should have known" that the patient lacked the skills and circumstances to implement the regimen effectively and "could have done something" to rectify this in the clinic visit. But the economy of the clinic visit places system constraints on provider capacity to engage either in lengthy processes of discovery or compensatory education. Additionally, of course, the need for such education may only be visible when the treatment fails, and so the failure of overly aggressive regimens may be ultimately beneficial if it can point to changes that later allow more aggressive treatment to be successfully attained.

The mutability of goals (e.g., the expectation that they will be "individualized" and adjusted in unspecified ways for "certain populations") in chronic illness management is a practical necessity even as it undermines basic assumptions about error and QA that are implicit in much research and thinking about them. Additionally, as above examples make clear, the active role of patients in diabetes care creates a very strong rhetorical framework for attributing shortcomings in treatments to patients and away from providers. To the degree that patients have the potential to derail providers' treatment plans and goals, providers are less accountable for the outcomes of treatment. We wish merely to note this point as a complicating feature for the understanding of error in the treatment for chronic illness, not to suggest that this shift in accountability is improper. That said, patients of low socioeconomic status are less likely than patients of high socioeconomic status to be able (and, perhaps, willing) to execute the complex treatment regimens that are most likely to ward off complications (Goldman & Smith, 2002). It is within these challenging circumstances that some providers systematically modify their treatment goals, and thus these findings may implicate health disparities (Lutfey & Freese, 2005).

Resistances to guidelines and standardization

Findings of practice variation have served importantly to motivate quality improvement studies. In acute care settings, efforts at error reduction and quality improvement often focus on identifying best practices and attempting to standardize their use. In the case of guidelines for diabetes care, providers expressed frustration that explicit targets were unhelpful for the individualization they must undertake in treating patients. Many providers were not responsive to what they perceived as efforts to police providers over poorly conceived criteria. In this way, the ambiguities inherent in diabetes care may provide grounds for resisting efforts to use standardization to improve care.

As examples, one provider claimed to receive 10 letters per week from insurance companies, querying about specific patients who had not been documented as having received some standard of care (e.g., having an annual eye exam or achieving a specific glucose level). When we asked if he responded to these letters, he laughed and said that he throws them away; when we asked if he thought his colleagues responded to such letters, he laughed even more, and replied, "No. Well, actually we put them in the shredder." Another provider elaborated his perspective on regulators (which he called "bean counters") as follows, explaining how he sometimes has systematic reasons for not adhering to guide-lines:

You get something in the mail that says you're not taking care of your patients as well as you should... By reflex, it makes the hair on your neck stand up, and you're like, "Well, how dare somebody 800 miles away send me a letter and tell me I don't know how to take care of my patients, when they haven't probably ever seen a patient?" Or maybe they're looking at some guideline, drawing an arbitrary line, and calling me a bad doctor because my patient isn't getting an eye exam every year... Maybe I don't think they need an eye exam every year.... Or maybe their A1c isn't below seven, but maybe they have severe hypo-unawareness, and they've crashed their car last week and we're raising their goal to try to save their life. I mean, these are real clinical situations that don't show up in the guidelines. Bean counters just need to realize these things.

Most immediately, the latter comment illustrates the tension wherein providers are trying to customize their treatment strategies in ways that are tailored to individual needs, and diabetes practice guidelines are poorly suited to regulate that process. A standard stating that patients should have HbA1c levels below 8—at least if taken as implicating "failure" so long as this standard is not reached is not going to capture the complexity and contingency of the process this physician describes. As a result, the provider is frustrated and disregards the criteria as insufficiently sophisticated to guide his work beyond abstract goals of where glucose levels should ideally be. Indeed, the obvious inadequacy of guideline targets for some patients may make it easier to flout evidence-based guidelines for aspects of practice in which physician discretion is more questionable (e.g., "maybe I don't think they need an eye exam every year"). The practical exigencies of diabetes care provide ample and obvious reason why medical care can treat the uniform goals implicit in standards as unrealistic or inappropriate for certain patients, as the inability to meet standards can so plainly occur for circumstances for which neither the doctor nor the medical system can be considered accountable by any usual vocabulary of error.

Put another way, the sorts of expert judgment involved in customizing treatments, as well as the complex causality described above, inherently allows providers more latitude in accounting for their work as non-error. These examples-as well as the earlier excerpt in which a physician talked about how errors could be readily attributed to the progression of the disease-may thus point more broadly to ways in which diabetes care may intersect with features of the medical profession that inhibit error analysis. As past research has demonstrated, the historical emergence of the medical profession was contingent on protecting it from external challenges to its authority (Freidson, 1970; Sharpe & Fadin, 1998; Starr, 1982), and this was facilitated by, for example, the initial cohesion of the AMA, expectations of collegiality (Bosk, 1979), and internal social control and regulation of problems (Sharpe & Fadin, 1998). In this context, the problem of providers portraying themselves as unaccountable to practice guidelines they view as unreasonable may be about more than particular guidelines or other QA measures not being the "right" intervention. Instead, it may signal ways that providers in chronic illness care could resist QA efforts more broadly and thus insulate against regulation and standardization.

Discussion

An important goal of *To Err is Human* and subsequent work inspired by it, has been to try to "change the conversation" about medical error from one of blaming "miscreant clinicians" to one

of thinking in terms of "systems failures" (Leape & Berwick, 2005, p. 2384). The effort seeks to move away from attributing blame to lapses by individuals to interrogating the system of care for processes that permit lapses to result in patient harm. Following from this shift in the conceptualization of error, real failure is no longer a matter of individual mistakes, but of an uncorrected system that allows mistakes to happen repeatedly. Standardization of treatment provides a linchpin for developing and implementing system protections both for preventing injury and increasing effectiveness. Insofar as evidence-based practice guidelines offer parameters for treatment that do not rely solely on the discretion and decision making of individual providers, they function as vehicles for such standardization.

This strategy for protecting healthcare from individual lapses has found some success in some acute care environments, but the vocabulary of "medical error" is more limited in its appropriateness for the work of clinicians in chronic illness management. We observe that ambiguities introduced by differences between acute and chronic care create problems with the definition of adverse events, the collection of relevant information in an impoverished environment, the determination of long-term treatment goals, and the application of standardization efforts. To be more effective, a conceptual framework for thinking about medical error in chronic illness management needs to account for processual, iterative treatment decisions and outcomes; the active role of patients and how they affect the design, execution, and success of treatment plans; the probabilistic and often temporally distant relationship between treatments and outcomes; and the ongoing need for providers to customize treatments according to patients' needs and abilities.

The policy implications of these findings are numerous. As a general principle, they suggest the benefit of continuing to increase the role that social science research might play in informing those aspects of guidelines that pertain to patient behavior and provider-patient interaction. Rather than simply suggesting that goals should be individualized and that certain populations may need special consideration, practice guidelines could draw on sociological and psychological research that provide specific information about how people gather and process information, how they make health behavior decisions, and how patient-provider interaction shapes health outcomes. Existing guidelines on adapting diabetes care for specialized populations still draw on a modest evidence base (e.g., Brehove et al., 2002). By drawing on this kind of research to inform practice guidelines, authors of practice guidelines may be better positioned to assist providers and patients in improving quality despite some of the ambiguities that we describe here.

In this respect, our findings support efforts to extend the guiding ethos of the medical error paradigm-using system safeguards to protect against lapses in individual judgments-to patients with chronic illnesses along the lines proposed by the "chronic care model" (Bodenheimer et al., 2002). As long as strong efforts are underway to change conversation away from blaming miscreant physicians, progress might also be made against blaming "miscreant patients" as well. Many providers already describe the work of "playing detectives" in attempting to figure out solutions to problems of non-adherence. Excepting egregious failures, detectives are usually not thought to have erred just because they cannot solve a case, and blame for non-adherence is more naturally shouldered by the non-adherent patient. By treating patient behavior as part of the system requiring safeguards, behaviors can be treated as prompting more thorough intervention than they do now. For instance, patients presenting with chronically high HbA1c levels could be automatically referred to a diabetes educator or other allied health specialist as a way of preventing "clinical inertia" (Phillips et al., 2005). While understanding that patients may fail to reach standard targets for many reasons, persistent failures could still be used to prompt more automatic inquiry, especially by practitioners who may have more time and specialized knowledge for "playing detective." We see this possibility as resonant with other calls to expand the use of "teams" (especially for lower SES populations) as basic to improving quality of care in chronic illness settings (Siminerio et al., 2006).

Furthermore, rather than focusing on striving for or achieving a specific glucose level, it might be better to incorporate a vocabulary for understanding improvement: Has a patient's glucose level improved in a given year? Have significant barriers to glucose control been addressed in the last year? Rather than focusing on what counts as a mistake in a long-term situation, it may be more productive to focus policy efforts on weak points in the system where overall glucose levels could be improved by modifications in the system. For example, one potential area for policy development may include working for improved accuracy in providers' assessments of patient adherence (and, by extension, their assessments of the glucose control a patient may be able to achieve). By extension, policy efforts could focus more on distributing resources in ways that increase low SES patients' access to educators and social workers, and provide reimbursement structures to physicians that give them better tools for making accurate patient assessments and increasing patients' abilities to be more successful in managing glucose.

Conclusion

In this paper, we draw from ethnographic and interview data to consider the nature of the detailed. everyday work that diabetes care providers do, and how ambiguities present in chronic illness care may elude the acute care focus implicit in the vocabulary of the medical error paradigm. These data address only one chronic illness, diabetes, and are taken from two clinics in teaching hospitals. On a purely speculative basis, we would expect similar problems to arise in the management of other chronic illnesses in other types of organizational settings, as the gradual unfolding of health outcomes makes it difficult to assess causality and potential interventions. However, there is a need for future research that expands the analyses we have presented here and considers the implications of that work for health policy, specifically the ways in which interventions designed to decrease medical mistakes can be more smoothly matched to the uncertain and iterative nature of chronic illness care.

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References

- American Diabetes Association. (2006). Standards of medical care for patients with diabetes mellitus—2006. *Diabetes Care*, 29(Suppl. 1), S4–S42.
- Bodenheimer, T., Wagner, E. H., & Grumbach, K. (2002). Improving primary care for patients with chronic illness: The chronic care model, part 2. *Journal of the American Medical Association*, 288, 1909–1914.
- Bosk, C. (1979). Forgive and remember: Managing medical failure. Chicago: University of Chicago Press.
- Brehove, T., Bloominger, M. J., Gillis, L., Meierbachtol, D. A., Richardson, V. J., & Strehlow, A. J. (2002). Adapting your practice: Treatment and recommendations for homeless patients with diabetes mellitus. Nashville, TN: Health Care for the Homeless Clinicians' Network, National Health Care for the Homeless Council, Inc.
- Fox, R. (1957). Training for uncertainty. In R. K. Merton, G. Reader, & P. Kendall (Eds.), *The student-physician* (pp. 207–241). Cambridge: Harvard University Press.
- Freidson, E. (1970). *Profession of medicine*. Chicago: University of Chicago Press.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago, IL: Aldine Publishing Co.
- Goldman, D., & Smith, J. (2002). Can patient self-management help explain the SES health gradient? *Proceedings of the National Academy of Sciences*, 99, 10929–10934.
- Hayward, R. A., & Hofer, T. P. (2001). Estimating hospital deaths due to medical errors. *Journal of the American Medical Association*, 286(4), 415–420.
- Institute of Medicine. (2000). *To err is human: Building a safer health system*. Washington, DC: National Academy Press.
- Leape, L. L., & Berwick, D. M. (2005). Five years after to err is human: What have we learned? Journal of the American Medical Association, 293, 2384–2390.
- Leape, L. L., Brennan, T. A., Laird, N., Lawthers, A. G., Localio, A. R., Barnes, B. A., et al. (1991). The nature of adverse events in hospitalized patients: Results of the Harvard

medical practice study II. New England Journal of Medicine, 324(6), 377–384.

- Light, D. W. (1972). Psychiatry and suicide: The management of a mistake. *American Journal of Sociology*, 77(5), 821–838.
- Lutfey, K., & Freese, J. (2005). Toward some fundamentals of fundamental causality: Socioeconomic status and health in the routine clinic visit for diabetes. *American Journal of Sociology*, 110, 1326–1372.
- McDonald, C. J., Weiner, M., & Hui, S. L. (2000). Deaths due to medical errors are exaggerated in Institute of Medicine report. *Journal of the American Medical Association*, 284, 95–97.
- Millman, M. (1977). The unkindest cut: Life in the backrooms of medicine. New York: William and Morrow and Co., Inc.
- Paget, M. A. (1988). The unity of mistakes: A phenomenological interpretation of medical work. Philadelphia: Temple University Press.
- Phillips, L. S., Ziemer, D. C., Doyle, J. P., Barnes, C. S., Kolm, P., Branch, W. T., et al. (2005). An endocrinologist-supported intervention aimed at providers improves diabetes management in a primary care site. *Diabetes Care*, 28, 2352–2360.
- Pope, C. (2002). Contingency in everyday surgical work. Sociology of Health and Illness, 24(4), 369–384.
- Rozich, J. D., Howard, R. J., Justeson, J. M., Macken, P. D., Lindsay, M. E., & Resar, R. K. (2004). Standardization as a mechanism to improve safety in health care. *Joint Commission Journal on Quality and Safety*, 30(1), 5–12.
- Sharpe, V. A., & Fadin, A. I. (1998). Medical harm: Historical, conceptual, and ethical dimensions of iatrogenic illness. New York: Cambridge University Press.
- Siminerio, L. M., Piatt, G. A., Emerson, S., Ruppert, K., Saul, M., Solano, F., et al. (2006). Deploying the chronic care model to implement and sustain diabetes self-management training programs. *Diabetes Educator*, 32, 253–260.
- Starr, P. (1982). The social transformation of American medicine. New York: Basic Books.
- Thomas, E. J., Studdert, D. M., Burstin, H. R., Orav, E. J., Zeena, T., Williams, E. J., et al. (2000). Incidence and types of adverse events and negligent care in Utah and Colorado. *Medical Care*, 38(3), 247–249.