

Medical Care Research and Review

<http://mcr.sagepub.com/>

Improving Methods for Measuring Quality of Care : A Patient-Centered Approach in Chronic Disease

Barbara G. Bokhour, Mary Jo Pugh, Jaya K. Rao, Ruzan Avetisyan, Dan R. Berlowitz
and Lewis E. Kazis

Med Care Res Rev 2009 66: 147 originally published online 11 December 2008

DOI: 10.1177/1077558708327174

The online version of this article can be found at:

<http://mcr.sagepub.com/content/66/2/147>

Published by:



<http://www.sagepublications.com>

Additional services and information for *Medical Care Research and Review* can be found at:

Email Alerts: <http://mcr.sagepub.com/cgi/alerts>

Subscriptions: <http://mcr.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

Citations: <http://mcr.sagepub.com/content/66/2/147.refs.html>

>> [Version of Record](#) - Mar 4, 2009

[Proof](#) - Dec 11, 2008

[What is This?](#)

Improving Methods for Measuring Quality of Care

A Patient-Centered Approach in Chronic Disease

Barbara G. Bokhour

*Edith Nourse Rogers Memorial Veterans Affairs Medical Center, Bedford, MA
Boston University School of Public Health, Boston*

Mary Jo Pugh

*South Texas Veterans Health Care System, Veterans Evidence-Based Research
Dissemination Implementation Center Research Enhancement Award Program,
San Antonio*

University of Texas Health Science Center at San Antonio

Jaya K. Rao

*Healthy Aging Program, National Center for Chronic Disease Prevention and
Health Promotion, Centers for Disease Control and Prevention, Atlanta, GA
Emory University School of Medicine, Atlanta, GA*

Ruzan Avetisyan

Boston University School of Public Health, Boston

Dan R. Berlowitz

Lewis E. Kazis

*Center for Health, Quality, Outcomes & Economic Research, Edith Nourse Rogers
Memorial Veterans Affairs Medical Center, Bedford, MA
Boston University School of Public Health, Boston*

As health care systems seek to provide patient-centered care as a cornerstone of quality, how to measure this aspect of quality has become a concern. Previous development of quality indicators for treating individual chronic disease has rarely included patient perspectives on quality of care. Using epilepsy as an exemplar, the authors sought to develop an approach to measuring patient-centered quality of care. They conducted six focus groups with adults with epilepsy. Using qualitative methods, the authors initially identified 10 patient-generated quality indicators, 5 of which were subsequently rated, along with literature-based quality indicators, by an expert panel using a modified RAND appropriateness methodology. The authors discuss similarities and differences in aspects of care patients and providers value as essential for good quality. The process presented in this article may serve as a model for incorporating patient perceptions of quality into the future development of quality indicators for chronic diseases.

Keywords: *quality indicators; patient-centered care; chronic disease; epilepsy; qualitative methods*

In recent years, the quality of health care has gained recognition as an important societal concern and has become the focus of health policy and research (Chassin, Galvin, & National Roundtable on Health Care Quality, 1998). In 2000, the Institute of Medicine (IOM) published its landmark study "Crossing the Quality Chasm," indicating serious problems throughout the health care system resulting in widespread quality problems (Committee on Quality Health Care in America & IOM, 2001). The IOM (1990) defined *quality* as "the degree to which health care services for individuals and populations increase the likelihood of desired outcomes and are consistent with current professional knowledge" (p. 44). Central to this definition is that the desired outcomes be consistent not only with clinical goals but also with patients' own goals. Consequently, in addition to considering safety, effectiveness, timeliness, efficiency, and equity of care, the IOM emphasized the importance that such care be patient centered. To be patient centered, the care must be sensitive, empathic, and responsive to each individual's needs, preferences, and values (IOM, 1990). Others have further advocated that truly patient-centered care can only be achieved when patients and professionals work together to create systems of care that integrate both patient and provider perspectives (Delbanco et al., 2001).

And yet, as the IOM and other agencies seek to develop measures of quality, few investigators to date have focused on developing patient-centered indicators of quality for specific chronic diseases (Spencer, Steinberg, Mali, Adams, & Litwin, 2003). Patient perspectives and preferences are often disregarded as valid evidence for clinical guidelines or quality indicators, a gap that has gained increasing attention (Krahn & Naglie, 2008). Although measures of patient perspectives on quality have been developed, such as the Consumer Assessment of Health Providers and Systems Survey (CAHPS; Cleary & Edgman-Levitan, 1997; Crofton, Lubalin, & Darby, 1999; Davies et al., 2008), few of these are specific for individual diseases, and none have been integrated with the measurement of clinical indicators of quality. In this article, we propose a method to develop patient-centered quality indicators for epilepsy as a model for developing quality measurement for a specific chronic disease. Epilepsy is a prime example of a common chronic disease in which both the disease and its treatment have a profound effect on the daily lives of patients (Fisher et al., 2000a, 2000b). Moreover, several studies have raised concerns regarding the

Authors' Note: This article, submitted to *Medical Care Research and Review* on February 8, 2008, was revised and accepted for publication on September 15, 2008.

This study was supported by a grant from Centers for Disease Control (ASPH S3492). We would like to thank all the participants and the expert panel members for their time and effort. We thank focus group leaders Dharma Cortes and Leslie Roberts and research assistants Gabriel Shapiro, Victoria Anne Nethercot, Meenu Tuteja, Aghogho Okparavero, and Ventrice Shillingford. The views expressed in this article are those of the authors and do not necessarily represent the views of the Department of Veterans Affairs. A version of this article was presented at the Society of General Internal Medicine meetings, April 2007, Toronto, Ontario, Canada.

quality of epilepsy care, indicating the need for a better epilepsy-specific measurement (Boylan et al., 2004; Pugh, Cramer, & Knoefel, 2004).

We conducted the Quality Indicators in Epilepsy Treatment (QUIET) study to identify a series of key indicators for measuring the quality of care provided to adults with epilepsy. Following the RAND methodology for developing quality indicators (Brook, 1994), we identified 25 quality indicators for epilepsy based on a review of the evidence for high-quality epilepsy care in the literature (Pugh et al., 2007). However, unlike previously developed quality indicators for chronic diseases (Kerr, Asch, Hamilton, & McGlynn, 2000), these 25 indicators included patients' perceptions of high-quality epilepsy care to assure that quality indicators were also patient centered. Using results of patient focus groups, we identified patient-generated quality indicators (PGQIs). This article describes the process through which these PGQIs were established and discusses the subsequent rating of these indicators by a panel of epilepsy clinical experts.

New Contribution

Methods for measuring health care processes and outcomes are a necessary part of quality improvement. To date, quality of care measurement strategies have focused primarily on medically focused processes and outcomes that can be assessed through the use of administrative data. Quality indicators that are based on administrative data can provide information on the technical aspects of care, such as providers' use of appropriate medications or testing strategies and whether patients attained a desirable degree of disease control. These types of indicators are usually determined by a group of clinician experts based on clinical evidence and do not consider the crucial perspectives of patients regarding the quality of care they receive.

Reliance on administrative data limits the possibility of measuring patient perceptions of quality. During the past several years, a focus on patient perceptions of care and patient satisfaction has emerged as an important concern in health care systems. Several authors have distinguished between patient satisfaction and patient perceptions of care, stating that patients may well be satisfied with their care and still perceive limitations in the care they receive (Epstein, Laine, Farber, Nelson, & Davidoff, 1996; Safran et al., 1998; Sofaer & Firminger, 2005). Subsequently, several studies have sought to develop distinct measures of patients' perspectives of health care quality.

Generic measures of patient satisfaction with and perceptions of primary care have been developed and well validated (Cleary & Edgman-Levitan, 1997; Crofton et al., 1999; Davies et al., 2008). Notably, the CAHPS surveys, which incorporate many aspects of patient-centered care, have been useful in describing patients' perceptions of health care quality and satisfaction across different health plans and settings over time (Cleary & Edgman-Levitan, 1997; Davies et al., 2008). Other investigators have used qualitative methods to examine different types of patients'

perspectives of quality of primary care and nursing care (Sofaer & Firminger, 2005). These studies consistently demonstrate that, in addition to technical aspects of care, patients consider access and interpersonal relationships (e.g., communication with providers and staff) as critical elements of quality health care (Laine et al., 1996; Sofaer & Firminger, 2005).

Generic primary care assessment measures such as those described, however, are unlikely to touch on patients' quality concerns that may be unique to particular chronic illnesses such as epilepsy. The development of such tools to assess aspects of quality care that patients identify as central to their care for specific chronic illnesses is lacking. Furthermore, patients' perceptions of the quality of health care they receive have been assessed independently from the measurement of health care performance through quality indicators. No study has developed methods for integrating patient perceptions into the development and implementation of patient-centered quality indicators for specified chronic diseases. Use of patient-centered indicators would help focus quality measurement on aspects of health care that matter most to patients. Our proposed approach incorporates the patient's perspective into the development of patient-centered quality indicators for a particular chronic illness. By identifying and integrating patient-generated indicators with those that are based on clinical evidence, we highlight the value of developing a set of quality indicators that reflect the perspectives of two experts in the clinical encounter: patients and clinicians.

Method

Overview

This study involved two phases. In the first phase, we conducted focus groups of adults with epilepsy to elicit their perspectives on what constituted quality epilepsy care and identify preliminary patient-generated indicators. Qualitative methods can be useful for exploring previously understudied phenomena such as patients' perspectives on quality (Patton, 2002). Qualitative studies with patients have led to a deeper understanding of quality in many different areas and have served as the foundation for establishing measures of patient satisfaction and perceptions of quality of care such as the CAHPS (Sofaer & Firminger, 2005). These methods allow researchers to begin to understand patients' perspectives on their experiences in obtaining care for epilepsy and on what constitutes good versus poor quality of care. In the second phase of the study, we performed a modified Delphi Process with clinician experts, who rated the patient-generated indicators for their applicability to quality epilepsy care. This study was approved by the Boston Medical Center Institutional Review Board.

Patient Focus Groups

Focus group participants. We used a purposeful sampling method in which researchers select particular groups of participants based on the literature or theories regarding the area of interest (Silverman, 2006). The assertion of initial primary comparison groups is a common sampling technique for qualitative studies (Trost, 1986). Our sampling scheme is designed to ensure informative contrasts of patients with epilepsy according to patient gender and race/ethnicity. Epilepsy and epilepsy treatment are known to have gender-specific effects, such as effects on pregnancy or menstrual cycles (Crawford, Appelton, Morrow, & Group, 1999); therefore, we recruited both men and women to participate in separate focus groups.

Furthermore, in the case of quality of care, there is extensive literature indicating that African Americans and Hispanics have different perceptions of quality than Whites. In particular, issues of discrimination are more commonly found in these groups (Fiscella, Franks, Gold, & Clancy, 2000; Smedley, Stith, Nelson, & Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, 2002). Because the medical center where we conducted this research predominantly serves African American, Hispanic, and White patients, we focused on these groups rather than other racial or ethnic groups.

Using administrative data from a neurology department at a major medical center, we identified 300 patients with an International Classification of Diseases, Clinical Modification code indicative of epilepsy (345.xx, 780.39) during the previous 2 years. A letter describing the study was sent to this cohort of potential participants. Following this mailing, potential participants were contacted by telephone and asked whether they would like to participate in a focus group discussion. During this call, participants were asked a series of eligibility questions. Inclusion criteria were (a) patients' reporting having been told they had a diagnosis of epilepsy or seizure disorder; (b) self-reported ethnic/racial identity as African American, White, or Hispanic; and (c) 18 years of age and older. Patients were excluded if they reported they would be unable to actively participate in a 1.5 hr meeting. Any participant who was eligible and able to attend a focus group at one of several predetermined times was included in the study; this eliminated many potential participants, as scheduling was complicated. Once 8 to 10 participants agreed to attend a focus group, recruitment for that group ended. Although we sought to include a range of patients according to age, we did not use age as a criterion for participation. Because we were interested in understanding the care provided to patients with various types of epilepsy, seizure frequency, and severity, there were no eligibility criteria based on specific type of epilepsy or severity.

Focus group procedures. We conducted six focus groups stratified by gender and race/ethnicity. The groups were led by an experienced race/ethnicity concordant

Table 1
Focus Group Guide

We are interested today in talking about your experiences with epilepsy and the care you have received for your epilepsy, both here at this medical center and from other providers.

We'll start by going around and having everyone introduce themselves.

1. Tell us a little about yourselves. How old you are, where you live, what you do for a living, your family life.
2. Tell a little about your experience with epilepsy.
3. Can anyone recall a time when they were particularly happy with the care they received for epilepsy? Particularly unhappy with the care they received?
 - a. What made it good/bad?
 - b. What would you like to have seen done differently?
 - c. What was the outcome?
4. Has anyone ever had difficulty getting what he or she needed for his or her epilepsy?
 - a. Probes: getting to see your physician; getting the medications; getting the treatment you thought you should have; paying for care; insurance issues; seeing a specialist when you wanted.
5. Let's talk about your doctors. Do you like your doctors?
 - a. Do you think he or she is a good doctor for epilepsy? For other medical issues?
 - b. What makes for a good doctor for epilepsy?
 - c. What would you like to see change with your doctors?
6. Has anyone ever felt as if the care he or she got wasn't as good as someone else's care?
 - a. Why do you think that was the case?
 - b. Did you feel as if this was because of your gender, race, ethnicity, or education?
7. If you could have anything except for a perfect cure for your epilepsy, what would your medical care look like?
8. If the following are not discussed above, add:
 - a. Have you ever felt that the treatment you are getting put you at risk or wasn't safe? Can you tell us about that?

Note: The focus group guide was used in a semistructured manner, moving through different topics as they were raised by participants. Questions were not necessarily asked in order, but all topics were discussed in all groups.

moderator. The focus group methodology was chosen because the conversation between participants engenders discussion of issues that may not arise in individual interviews (Kitzinger, 1994). We stratified the groups according to gender and race/ethnicity to best facilitate discussion of sensitive issues, such as sexuality, women's health issues, and experiences of discrimination, that may not have occurred in mixed groups.

Each focus group lasted approximately 1.5 hr. Patients received a \$50 gift certificate for their participation. The focus group moderator followed a semistructured interview guide designed to elicit patients' experiences with care for their epilepsy and their perceptions of what constitutes good quality of care (see Table 1). We initiated the discussion by telling patients that we were interested in understanding what constituted good or poor quality care from their perspective. During the focus

groups, patients were asked to describe their experiences with epilepsy and their experiences with providers and the health care system in obtaining and sustaining treatment for epilepsy; they were asked to describe instances of excellent care and poor care, and they were asked to identify key characteristics of each type of care. Focus groups were digitally audio-recorded.

Participants also responded to a brief written sociodemographic questionnaire prior to the start of the focus group. Verbal consent was obtained at the time of telephone screening, and written informed consent was obtained from all participants at the time of the focus groups.

Focus group analysis. Focus group audio-recordings were fully transcribed, and patient names were replaced with pseudonyms. Two investigators conducted grounded thematic analysis of verbatim transcripts informed by grounded theory (Strauss, 1987). This method involves a series of open coding of transcripts in which all emergent themes—concerns and issues that patients raised regarding the care they received for their epilepsy—were identified. Through discussion between two investigators, this process was then followed by axial coding, involving sorting and classifying of selected codes into major themes. Using constant comparison analysis of themes and associated segments of transcripts, we identified key repeated themes, themes that arose in all groups or involved extended discussion in one or two groups. We identified exemplary patient statements reflecting specific themes. Based on these, we generated 10 quality indicators, which were subsequently rated by the clinician expert panel, using the form “Providers should”

Clinician Expert Panel

Clinician expert panel participants. We invited 15 individuals who were general neurologists, epileptologists with national or international reputations, epilepsy social workers, and epilepsy nurses to participate in an expert panel to identify quality indicators for epilepsy. These individuals were selected based on their experience diagnosing and treating people with epilepsy, and they included individuals with both community and academic practices. From this group, 11 physicians agreed to participate in an expert panel to identify key quality indicators for epilepsy quality of care. These individuals worked in both academic and clinical settings and included a geriatrician and 10 epileptologists. Ten of these clinician experts participated in the first round of rating the PGQIs at the face-to-face meeting, and 9 provided ratings for the second round via mail.

Clinician expert panel procedures. To determine the appropriateness (validity) of the proposed PGQIs, we used a modification of the RAND appropriateness method (Brook, 1994; Fitch et al., 2001). The RAND appropriateness method involves a modified Delphi approach in which a panel of experts views evidence, rates quality

indicators, receives feedback, and rates the indicators a second time. This method has been found to have content, construct, and predictive validity (Brook, 1994; Shekelle, Chassin, & Park, 1998). The PGQIs were presented at a clinician expert panel face-to-face meeting, during which other indicators generated through traditional clinical literature review were being evaluated. Although the PGQI's were evaluated similarly to the clinical indicators presented, the evidence was presented somewhat differently from the way clinical indicators were. Each PGQI was presented in the form "Providers should . . .," and evidence was provided in the form of direct quotes from focus group participants with descriptions of discussions in the focus groups from one investigator (B.G.B.). Panel members were given the opportunity to discuss the indicators at that time and ask questions about the focus group discussions, and then, they rated each indicator. Feedback, in the form of distribution of scores, was provided to the clinician experts after the meeting, and a final rating round was conducted by mail.

The PGQIs were rated initially on two dimensions: appropriateness and feasibility. Using definitions from the RAND Appropriateness Method (Fitch et al., 2001), an *appropriate indicator* was defined as a process of care in which the benefits far outweighed the potential risks, regardless of cost, and that was believed to represent high quality of care. A *feasible indicator* was defined as one that could be reliably measured. For instance, if it was unlikely that data would be available in patient charts or through a patient survey, a measure—regardless of appropriateness or validity—would be of little value in assessing quality. All indicators that were rated as appropriate were then rated for necessity. A *necessary indicator* was defined as a process in which failure to recommend would be viewed as improper clinical judgment. An indicator could be defined as *appropriate*, but not *necessary*, meaning that while the process described in the indicator might be considered by the clinician experts to be beneficial to the patient, they would not consider it essential to good care (Fitch et al., 2001).

For each round of ratings, indicators were rated on a 9-point Likert-type scale: Ratings of 1 to 3 indicate that the item is not an appropriate, reliable, or necessary measure of quality; ratings of 4 to 6 indicate that the item is uncertain or equivocal; and ratings of 7 to 9 indicate that the item is clearly appropriate, reliable, or necessary.

Clinician expert panel analysis. For each phase of the rating process, we determined the median panel rating and a measure of dispersion for each PGQI. Items with a median of 7 or higher without disagreement were classified as appropriate quality indicators. As there were 10 panel members, we used definitions of *agreement* and *disagreement* described by the BioMed Concerted Action on Appropriateness (Fitch et al., 2001). Accordingly, items on which three or more panelists rated in the lower (1 to 3) and upper (7 to 9) extremes were classified as having disagreement. Items in which two or fewer panelists rated outside the 3-point

region containing the median (1 to 3, 4 to 6, and 7 to 9) were classified as having agreement.

Results

Focus Groups and Identification of PGQIs

Thirty-five patients participated in six focus groups. Demographic characteristics of the participants can be found in Table 2. Patients ranged in age from 24 to 76; were well distributed among Latino, White, and African American backgrounds; and almost half were women. Most of the patients were receiving some form of public insurance, and 27 had incomes less than \$40,000 per year. This reflects the socioeconomic status of the population at the medical center where the study was conducted. Patients had a large range of educational backgrounds, and 20 were taking more than one anti-epileptic drug (AED) at the time of the study, indicating more severe epilepsy.

Open coding generated 60 different concerns and issues raised by patients with regard to their experiences with epilepsy care, such as a need for explanations and issues of trust in the provider and epilepsy treatment. Axial coding resulted in subsequent categorization identifying overarching quality of care concerns, such as communicating about medication side effects, needing more information about epilepsy, needing psychosocial support, the complexity of epilepsy treatment, and the impact of epilepsy and its treatment on women's health. These were then sorted into one of four overarching categories of quality of care: (a) access to care, (b) technical aspects of care, (c) communication between providers and patients, and (d) interpersonal aspects of care. As a result of this process, we identified 10 primary concerns, which were then worded as 10 PGQIs (see Table 3). These 10 indicators were presented to the clinician expert panel for discussion at the face-to-face meeting. After discussion, the 10 PGQIs were reduced to 5, and those were subsequently rated by panel members. This process is described later on in the section on clinician expert panel ratings.

Below, we discuss each of the five remaining indicators representing access to care, interpersonal aspects of care, and patient-provider communication and provide exemplary quotes from the focus groups. We then present the clinician expert panel ratings for each of the five indicators. PGQIs 1 and 2 relate to access to care issues, specifically access to social resources that would support patients' living with epilepsy. PGQIs 3 and 4 refer primarily to patient-provider communication as it relates to quality of care. PGQI 5 refers to interpersonal aspects of care.

Access to Care

PGQI 1: Providers should refer patients with epilepsy to local support groups or other resources to obtain psychosocial support. Repeatedly throughout the focus groups, patients stated that they felt isolated and had little contact with others with

Table 2
Demographics of Focus Group Participants

Demographics	Total (N = 35)
Age	
Average	46
Range	24 to 76
Race/ethnicity	
Caucasian	11
Hispanic	10
African American	14
Gender	
Men	18
Women	17
Insurance	
Medicaid/public	22
Private insurance	7
Free care	2
Uninsured	1
Missing	3
Annual income	
Less than \$15,000	16
\$15,000 to \$20,000	5
\$20,000 to \$40,000	6
\$40,000 to \$80,000	3
More than \$80,000	1
Missing	5
Education	
Less than 8th grade	3
9 to 11	4
High school graduate	12
Some higher education	8
College graduate	2
Postgraduate degree	3
Missing	3
Number of different AEDs	
1	12
2	10
3	8
4	2
Missing	3

Note: AED = anti-epileptic drug.

epilepsy. Those who did have the opportunity to meet with other individuals with epilepsy revealed the importance of obtaining psychosocial support. For example, one man said:

Table 3
Initial Patient-Generated Quality Indicators Based on Focus Group Analysis

Initial 10 Patient-Generated Quality Indicators	Result of Initial Discussion
1. Providers should refer patients to local support groups.	1. Retained
2. Providers should give referrals to social services to assist with employment, negotiating through SSDI, and so on.	2. Retained
3. Providers should provide patients with references to information about epilepsy through the Epilepsy Foundation and/or epilepsy Web sites.	3. Retained
4. Providers should communicate with patients about potential medication side effects, including cognitive, emotional, physical, and sexual side effects.	4. Retained
5. Providers should be honest with patients about the “inexact science” of epilepsy treatment and that there may be multiple trials of medication combinations before they find out what works best for them.	5. Retained
6. Providers should provide information about the impact of epilepsy and its treatment on other health conditions.	6. Blended with LGI
7. Providers should discuss potential long-term side effects of medications.	7. Blended with PGQI 4
8. Providers should explain epilepsy repeatedly, as many patients have memory loss.	8. Blended with LGI
9. Providers should discuss driving with patients. a. Providers should give information about alternative transportation to patients who can’t drive.	9. Blended with LGI a. Blended with PGQI 3
10. Providers should discuss impact of epilepsy and treatment on women’s health with respect to menstrual cycles, conception, pregnancy, and menopause.	10. Blended with LGI

Note: SSDI = social security disability insurance; LGI = literature-generated indicator; PGQI = patient-generated quality indicator.

I think that one thing that I need is . . . to go to support groups. That’s something that I have to do . . . to share my experiences with people. I have to do that.

At the end of one men’s focus group, several men said they had never before talked to someone else with epilepsy and that it was helpful to hear about others’ experiences. In the African American women’s focus group, participants spent time supporting each other about epilepsy and its effect on their lives and also agreed that they had little opportunity to share their experiences.

PGQI 2: Providers should refer patients with epilepsy to social services to assist with employment, negotiating social security disability insurance (SSDI), insurance, and alternative transportation for patients who cannot drive. Participants in all

groups described difficulties getting assistance in negotiating bureaucratic channels to applying for SSDI, getting access to alternative methods of transportation, and finding suitable employment. For example, one man stated that he had difficulty negotiating the system and wanted more assistance.

Patient–Provider Communication

PGQI 3: Providers should encourage patients to become educated about epilepsy and to advocate for themselves in the health care system and with providers. For example, providers should provide patients with written material about epilepsy and references to epilepsy foundation or epilepsy Web sites. Patients in all of the focus groups noted that they did not receive adequate information from their providers and needed to seek it out on their own via Internet searches or seeking out materials from the Epilepsy Foundation. They stated that they felt it would have been helpful if their providers had given them such materials, thereby empowering them to advocate for themselves through gaining knowledge about their disease. One woman praised her physician for doing just this:

[My doctor told me] that I had to be own advocate, to believe myself that I was right sometimes, you know, when I was talking about side effects. And right now you need to go out and learn as much as you can about this.

In contrast to this experience, another woman described accidentally finding some pamphlets from the epilepsy foundation, which gave her important information about medications and epilepsy that she had not learned from her provider. The onus of responsibility seemed often to be placed on the patients to obtain information on their own.

PGQI 4: Providers should communicate with patients about potential anti-epileptic medication side effects, including cognitive, emotional, physical, and sexual side effects. Discussions about side effects of medication were prominent in all the focus groups. Many patients complained of the side effects of the medication, from drowsiness and difficulty thinking to osteoporosis. Importantly, patients complained that they often were not warned of the side effects of a medication or that providers did not acknowledge the side effects they were experiencing. For example, one patient wanted physicians to:

instead of just giving the patient the medication and telling the patient this is for seizures, you let the patient also know of the side-effects of these medications that you're giving them.

Patients discussed experiencing side effects such as dizziness without knowing that this was a side effect of the medication. One of the men asked others if they, like

him, had experienced sexual side effects, and when others concurred, they also agreed that no provider had ever discussed this potential side effect. Sexual side effects were not a concern in the women's groups.

Interpersonal Aspect of Care

PGQI 5: Providers should discuss with patients the complexity of epilepsy treatment, explain that each patient responds to medications differently, and explain that they may need to try several different medications before they find out what works best for that individual. Throughout the focus groups, patients discussed the complexity of the treatment they received for epilepsy. Many described the changes in medication that occurred often, with one man even stating that he felt like a "guinea pig" as the doctors tried new medications to control his epilepsy. While most patients understood that epilepsy was complex, they also wished that providers would discuss this with them:

And I wish there would have been some way that as a scientist, as a doctor, the physicians would say we are going to be messing around for a while trying to find out what's right; and I don't want you to think I don't know what we're doing; but that's what this is. This is an inexact science, and we're working on finding what's right for you. Be patient.

It is interesting that the technical aspect of finding the correct medication, while important to patients, was overshadowed by their desire to know and understand the complexity of treatment. This indicator also referred to the more interpersonal aspects of care in that patients wished to be considered individuals with unique needs.

Clinician expert ratings of PGQIs

Based on an in-depth discussion of the initial 10 PGQIs during the clinician expert panel meeting, several PGQIs were identified as similar to another PGQI or quality indicators that had been generated through the initial clinical literature review (literature-generated indicator [LGI]) and therefore were blended with the LGI. For example, PGQI 9 addressed patients' concerns regarding driving, an issue that was addressed in an LGI stating that providers should tell patients with epilepsy not to drive. Subsequently, those PGQIs that were deemed redundant were eliminated, leading to five distinct PGQIs that were not subsumed in other indicators. Table 3 demonstrates which PGQIs were blended with other PGQIs or LGIs and which were kept for rating as one of the final five indicators. A summary of the clinician expert ratings of these indicators can be found in Table 4.

PGQI 1, on support groups, was rated as somewhat appropriate and feasible (rating 7.5), but the necessity of this indicator was rated as 6.0, or equivocal. During

Table 4
Expert Panel Ratings of Final Patient-Generated Quality Indicators

Appropriateness		Feasibility		Necessity	
Median	Rater Concordance	Median	Rater Concordance	Median	Rater Concordance
PGQI 1: Providers should refer patients with epilepsy to local support groups or other resources to obtain psychosocial support.					
7.5	Agreement	7.5	Agreement	6	Disagreement
PGQI 2: Providers should give referrals to social services to assist with employment, negotiating through SSDI, insurance and alternative transportation for patients who cannot drive.					
8.5	Agreement	7	Disagreement	7	Agreement
PGQI 3: Providers should encourage patients to become educated about epilepsy and to advocate for themselves in the health care system and with providers. For example, provide patients with written material about epilepsy, references to epilepsy foundation or epilepsy Web sites.					
9	Agreement	8	Disagreement	8	Agreement
PGQI 4: Providers should communicate with patients about potential medication side effects, including cognitive, emotional, physical, and sexual side effects.					
9	Agreement	7	Agreement	8	Agreement
PGQI 5: Providers should discuss with patients the complexity of epilepsy treatment and explain that patients respond to medications differently and that they may need to try several different medications before they find out what works best for them.					
8.5	Agreement	6.5	Disagreement	7	Disagreement

Note: PGQI = patient-generated quality indicators; SSDI = social security disability insurance.

the meeting, clinician experts argued that support groups were problematic, as patients often receive misinformation about epilepsy and treatment at such groups. There was, however, recognition of the need for psychosocial support for patients.

Clinician experts agreed that PGQI 2 on referral to social services was appropriate and necessary, but there was disagreement about the feasibility of measuring this aspect of quality. They believed that patients were in need of social services because addressing these concerns was beyond what providers could adequately address in most primary care clinical visits. They also commented that social services weren't always available for referral, particularly in more remote or rural areas.

Clinician experts rated PGQI 3 on self-advocacy highly throughout, with some disagreement about feasibility of measurement. Nonetheless, they believed it was important for patients to be well informed and to advocate for themselves. They further agreed that the resources available through the Epilepsy Foundation were most helpful for patients.

Clinician experts rated PGQI 4 on communicating about medication side effects as appropriate, feasible, and necessary, and there was agreement for all ratings. They

agreed that assessing and discussing medication side effects was critical to good quality care.

While clinician experts agreed that PGQI 5 on communicating about complexity was appropriate, they indicated it was not feasible to measure. They also disagreed regarding the necessity of this indicator for good quality of care. In particular, they argued that most patients would respond to the first medication prescribed, and therefore, engaging in a discussion of complexity and potential medication failure was not always needed.

Discussion

Measuring the quality of care provided to patients with chronic diseases such as epilepsy is essential to improving their health and health care experiences. Although clinician experts typically consider clinical research evidence when developing quality indicators, such indicators often focus on technical aspects of care and do not address the patients' perspectives on quality. We present a unique approach for incorporating patients' perspectives into the development of quality indicators for epilepsy care. We conducted focus groups to understand what constitutes quality care for epilepsy from the patients' perspective and identified quality indicators that reflect these perspectives. A panel of clinician experts rated the PGQIs as well as those that were based on research evidence to develop an overarching set of patient-centered indicators for quality epilepsy care. By using this approach to develop quality indicators, we increase the possibility of incorporating features of health care quality that are important to patients, such as access, communication, and interpersonal aspects (IOM, 1990), in addition to the technical aspects of care.

Our focus group findings indicate that patients value positive interpersonal interactions, clear communication about epilepsy and anti-epileptic medications, and improved access to psychosocial care. Our findings are similar to other studies in which patients identified their need for epilepsy care, information and advice on how to adapt to their condition, psychosocial support, and opportunities for more active participation in decision making (Elwyn et al., 2003; Swarztrauber, Dewar, & Engel, 2003). Previous work suggests that patients are unhappy with the information they receive about their epilepsy from providers (Sample, Ferguson, Wagner, Elisabeth Pickelsimer, & Selassie, 2006). The need for clear explanations and discussions about medication use and side effects is echoed in other literature suggesting that patients indicated that clear communication is a key aspect of quality of care (Groenewegen, Kerssens, Sixma, van der Eijk, & Boerma, 2005; Jacobi, Boshuizen, Rupp, Dinant, & van den Bos, 2004). Although many of these concerns around communication are also reflected in more general work on patient perceptions of care and may be measurable through the use of patient surveys such as CAHPS, several

concerns about side effects, for example, are specific to epilepsy. Similarly, patients with other chronic illnesses may have disease-specific quality concerns not captured by generic measures of patient satisfaction or patient perceptions of care.

Our findings also indicate that patients and clinician experts may have different opinions regarding what constitutes key aspects of quality of care. Other studies have found that patient perspectives on epilepsy care and outcomes differ from those of neurologists (Aldenkamp & Van Donselaar, 2003; Swarztrauber et al., 2003). Although in our study the clinician experts found all PGQIs to be appropriate and valid, and therefore, none were eliminated from the final list, the potential for disagreement raises a question: What should we do in cases where patient experts identify a key quality indicator and clinician experts decide that the indicator is inappropriate or unnecessary?

We propose that expanding our approach to include a process wherein patient experts would have the opportunity to review and rate the PGQIs in a process similar to the clinician experts' process would reinforce the emphasis placed on patient input. In cases where clinician experts determined a PGQI to be inappropriate or unnecessary, patient experts could be given an opportunity to review the clinician expert opinion and discuss them further. Such an approach would allow for a more direct comparison of patient and expert ratings of the same indicators and result in a set of indicators that may more closely reflect both clinician and patient perspectives on quality. In the case of patent discrepancies between patient expert and clinician expert ratings, it may be incumbent on the research team to evaluate the evidence provided by each group of experts and determine whether the clinical evidence outweighs the patient expectation or the patient perspective signifies a need for clinician education regarding a process of care. Balancing the perspectives of patients and providers regarding quality is vital to measuring and valuing patient-centered quality of care.

The clinician experts did indicate that it was not feasible to measure several of the PGQIs, but it is likely that they were only considering medical record reviews as a measurement strategy for assessing the PGQIs rather than patient surveys, which is likely to be a more effective measurement approach for PGQIs. One potentially paradoxical finding was that clinician experts found that it was feasible to measure the presence of discussions of medication side effects (PGQI 4) but not to measure the presence of discussions of the uncertainty that accompanies the effectiveness of these medications in treating each individual's epilepsy (PGQI 5). However, providers are increasingly being held responsible for the side effects that patients experience (Annas, 2008) and therefore are more likely to be documenting a discussion of side effects in the medical record. Subsequently, it may be more feasible to measure the presence of a discussion of side effects as opposed to one regarding the uncertainty of medication effectiveness, something that many providers find difficult to do, much less document, in many clinical situations (Politi, Han, & Col, 2007).

There are several limitations to our study. Our focus group participants were enrolled from a single neurology clinic in New England. All of the patients, therefore, had access to specialty care, which is not likely to be true of many patients suffering from epilepsy. We limited our sampling frame to African American, Hispanic, and White patients; patients from other ethnic groups may have different perceptions of quality not captured here. As more than half of the patients were taking more than one AED, they also reflect a population with more severe epilepsy. Although the expert panel members represented different geographical regions, all were physicians and the panel included only one primary care provider (a geriatrician), the others being neurologists and epileptologists. Individuals from other clinical areas of expertise (e.g., nursing, social work) reported that although travel to the meeting was paid by the study, they were unable to travel to the meeting because of work-related or family obligations. As a consequence, our panel's perspectives may not reflect those of other provider groups. Finally, as discussed earlier, the patients and clinicians in this study did not participate in a parallel process; future work in which patients rated PGQIs would enhance the validity of the indicators.

These findings have important implications for how we choose to measure quality of care. There may be debate regarding the relative weight of indicators generated from clinical literature and those generated from patients or what has recently been called "preference-related evidence" (Krahn & Naglie, 2008). And yet, if we are invested in improving all aspects of quality of care, we must begin to measure not only technical quality identified by clinician experts but also key aspects of quality that patient-experts deem critical. These aspects of care are especially important as providers seek to improve patients' abilities to take responsibility for engaging in chronic disease self-management (Hibbard, 2004). Our patients' request that care be tailored to the individual reflects the IOM's recommendation that patient-centered care "modify the care to respond to the person, not the person to the care" (Committee on Quality Health Care in America & IOM, 2001, p. 51). Patients reiterated this theme throughout their conversations about needing information about side effects so that providers alter medications according to individual patients' responses to medications.

Efforts to both measure and improve quality must incorporate patient-centered quality indicators to consider patient concerns on the same level as those of the experts. Our findings indicate there are differences between patients' and providers' perceptions about what constitutes good quality of care. The literature suggests that oftentimes providers do not take into account patients' expectations for care and outcomes and treatment goals (Heisler et al., 2003; Kravitz, Cope, Bhrany, & Leake, 1994). For epilepsy, as with many other chronic diseases, this seems especially vital as other data indicate that effective communication about medications and psychosocial issues may result in improvement in patients' adherence to medications and overall health status (Cegala, Marinelli, & Post, 2000; Roter et al., 1998). Because patient-centered care focused on interpersonal aspects of care has been

associated with higher quality of care (Meredith, Orlando, Humphrey, Camp, & Sherbourne, 2001), it is critical that patient perspectives be incorporated into new quality measures.

The process we present in this article may serve as an initial model for incorporating patient perceptions of quality into the future development of quality indicators for chronic diseases. As provider performance is increasingly measured based on quality indicators, this process will shift the focus toward a more patient-centered perspective of quality. The use of patient surveys on perceptions of quality of epilepsy care provided in both primary care and specialty clinics may inform health systems and payers regarding patient-centered quality. Furthermore, incorporating patient-centered quality indicators in pay-for-performance initiatives may reward providers for better communication and interpersonal skills and attention to other patient-centered concerns for those with chronic illness (Young et al., 2005).

References

- Aldenkamp, A. P., & Van Donselaar, C. (2003). Treatment of epilepsy in general hospitals: Do patients and neurologists agree on success or failure? *Seizure*, 12(8), 523-528.
- Annas, G. J. (2008). Doctors, drugs, and driving—Tort liability for patient-caused accidents. *New England Journal of Medicine*, 359(5), 521-525.
- Boylan, L. S., Flint, L. A., Labovitz, D. L., Jackson, S. C., Starner, K., & Devinsky, O. (2004). Depression but not seizure frequency predicts quality of life in treatment-resistant epilepsy. *Neurology*, 62(2), 258-261.
- Brook, R. (1994). The Rand/UCLA appropriateness method. In K. McCormick, S. Moore, & R. Siegel (Eds.), *Clinical practice guideline development: Methodology perspectives* (pp. 59-70). Rockville, MD: U.S. Department of Health & Human Services, Public Health Service, Agency for Health Care Policy & Research.
- Cegala, D. J., Marinelli, T., & Post, D. (2000). The effects of patient communication skills training on compliance. *Archives of Family Medicine*, 9(1), 57-64.
- Chassin, M., Galvin, R., & National Roundtable on Health Care Quality. (1998). The urgent need to improve health care quality: Institute of Medicine national roundtable on health care quality. *Journal of the American Medical Association*, 280(11), 1000-1005.
- Cleary, P. D., & Edgman-Levitan, S. (1997). Health care quality. Incorporating consumer perspectives. *Journal of the American Medical Association*, 278(19), 1608-1612.
- Committee on Quality Health Care in America, & Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.
- Crawford, P., Appelton, E., Betts, T., Duncan, J., Guthrie, E., Morrow, J., et al. (1999). Best practice guidelines for the management of women with epilepsy. *Seizure*, 8, 201-217.
- Crofton, C., Lubalin, J. S., & Darby, C. (1999). Consumer Assessment of Health Plans Study (CAHPS). Foreword. *Medical Care*, 37(Suppl. 3), MS1-MS9.
- Davies, E., Shaller, D., Edgman-Levitan, S., Safran, D. G., Oftedahl, G., Sakowski, J., et al. (2008). Evaluating the use of a modified CAHPS survey to support improvements in patient-centred care: Lessons from a quality improvement collaborative. *Health Expect*, 11(2), 160-176.
- Delbanco, T., Berwick, D. M., Boufford, J. I., Edgman-Levitan, S., Ollenschlager, G., Plamping, D., et al. (2001). Healthcare in a land called PeoplePower: Nothing about me without me. *Health Expectations*, 4(3), 144-150.

- Elwyn, G., Todd, S., Hibbs, R., Thapar, A., Edwards, P., Webb, A., et al. (2003). A 'real puzzle': The views of patients with epilepsy about the organisation of care. Retrieved September 1, 2007, from <http://www.biomedcentral.com/1471-2296/4/4>
- Epstein, K. R., Laine, C., Farber, N. J., Nelson, E. C., & Davidoff, F. (1996). Patients' perceptions of office medical practice: Judging quality through the patients' eyes. *American Journal of Medical Quality, 11*(2), 73-80.
- Fiscella, K., Franks, P., Gold, M. R., & Clancy, C. M. (2000). Inequalities in racial access to health care. *Journal of the American Medical Association, 284*(16), 2053.
- Fisher, R. S., Vickrey, B. G., Gibson, P., Hermann, B., Penovich, P., Scherer, A., et al. (2000a). The impact of epilepsy from the patient's perspective I. Descriptions and subjective perceptions. *Epilepsy Research, 41*(1), 39-51.
- Fisher, R. S., Vickrey, B. G., Gibson, P., Hermann, B., Penovich, P., Scherer, A., et al. (2000b). The impact of epilepsy from the patient's perspective II: Views about therapy and health care. *Epilepsy Research, 41*(1), 53-61.
- Fitch, K., Bernstein, S., Aguilar, M., Burnand, B., LaCalle, J. R., Lazaro, P., et al. (2001). *The Rand/UCLA appropriateness method user's manual* [MR-1269]. Santa Monica, CA: RAND Corporation.
- Groenewegen, P. P., Kerssens, J. J., Sixma, H. J., van der Eijk, I., & Boerma, W. G. W. (2005). What is important in evaluating health care quality? An international comparison of user views. *BMC Health Services Research, 5*(1), 16.
- Heisler, M., Vijan, S., Anderson, R. M., Ubel, P. A., Bernstein, S. J., & Hofer, T. P. (2003). When do patients and their physicians agree on diabetes treatment goals and strategies, and what difference does it make? *Journal of General Internal Medicine, 18*(11), 893-902.
- Hibbard, J. H. (2004). *Moving toward a more patient-centered health care delivery system*. Retrieved September 30, 2007, from <http://content.healthaffairs.org/cgi/content/abstract/hlthaff.var.133>
- Institute of Medicine. (1990). *Medicare: A strategy for quality assurance*. Washington, DC: National Academy Press.
- Jacobi, C. E., Boshuizen, H. C., Rupp, I., Dinant, H. J., & van den Bos, G. A. M. (2004). Quality of rheumatoid arthritis care: The patient's perspective. *International Journal for Quality in Health Care, 16*(1), 73-81.
- Kerr, E. A., Asch, S. M., Hamilton, E. G., & McGlynn, E. A. (Eds.). (2000). *Quality of care for general medical conditions: A review of the literature and quality indicators*. Santa Monica, CA: RAND.
- Kitzinger, J. (1994). The methodology of focus groups: The importance of interaction between research participants. *Sociology of Health & Illness, 16*(1), 103-121.
- Krahn, M., & Naglie, G. (2008). The next step in guideline development: Incorporating patient preferences. *Journal of the American Medical Association, 300*(4), 436-438.
- Kravitz, R. L., Cope, D. W., Bhargava, V., & Leake, B. (1994). Internal medicine patients' expectations for care during office visits. *Journal of General Internal Medicine, 9*(2), 75-81.
- Laine, C., Davidoff, F., Lewis, C. E., Nelson, E. C., Nelson, E., Kessler, R. C., et al. (1996). Important elements of outpatient care: A comparison of patients' and physicians' opinions. *Annals of Internal Medicine, 125*, 640-645.
- Meredith, L. S., Orlando, M., Humphrey, N., Camp, P., & Sherbourne, C. D. (2001). Are better ratings of the patient-provider relationship associated with higher quality care for depression? *Medical Care, 39*(4), 349-360.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Politi, M. C., Han, P. K. J., & Col, N. F. (2007). Communicating the uncertainty of harms and benefits of medical interventions. *Medical Decision Making, 27*(5), 681-695.
- Pugh, M. J., Berlowitz, D. R., Montouris, G., Bokhour, B. G., Cramer, J., Bohm, V., et al. (2007). What constitutes high quality of care for adults with epilepsy? *Neurology, 69*(21), 2020-2027.
- Pugh, M. J., Cramer, J., & Knoefel, J. (2004). Potentially inappropriate antiepileptic drugs for elderly patients with epilepsy. *Journal of the American Geriatrics Society, 62*, 417-422.

- Roter, D. L., Hall, J. A., Merisca, R., Nordstrom, B., Cretin, D., & Svarstad, B. (1998). Effectiveness of interventions to improve patient compliance: A meta-analysis. *Medical Care*, 36(8), 1138-1161.
- Safran, D. G., Kosinski, M., Tarlov, A. R., Rogers, W. H., Taira, D. H., Lieberman, N., et al. (1998). The Primary Care Assessment Survey: Tests of data quality and measurement performance. *Medical Care*, 36(5), 728-739.
- Sample, P. L., Ferguson, P. L., Wagner, J. L., Elisabeth Pickelsimer, E., & Selassie, A. W. (2006). Experiences of persons with epilepsy and their families as they look for medical and community care: A focus group study from South Carolina. *Epilepsy & Behavior*, 9(4), 649-662.
- Shekelle, P., Chassin, M., & Park, R. (1998). Assessing the predictive validity of the RAND/UCLA appropriateness method criteria for performing carotid endarterectomy. *International Journal of Technology Assessment in Health Care*, 14, 707-727.
- Silverman, D. (2006). *Interpreting qualitative data* (3rd ed.). Thousand Oaks, CA: Sage.
- Smedley, B. D., Stith, A. Y., Nelson, A. R., & Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. (Eds.). (2002). *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, DC: The National Academies Press.
- Sofaer, S., & Firminger, K. (2005). Patient perceptions of the quality of health services. *Annual Review of Public Health*, 26, 513-559.
- Spencer, B., Steinberg, M., Mali, J., Adams, J., & Litwin, M. (2003). Quality-of-care indicators for early-stage prostate cancer. *Journal of Clinical Oncology*, 21(10), 1928-1936.
- Strauss, A. L. (1987). *Qualitative analysis for social scientists*. Cambridge, UK: Cambridge University Press.
- Swarztrauber, K., Dewar, S., & Engel, J., Jr. (2003). Patient attitudes about treatments for intractable epilepsy. *Epilepsy & Behavior*, 4(1), 19-25.
- Trost, J. (1986). Statistically nonrepresentative stratified sampling: A sampling technique for qualitative studies. *Qualitative Sociology*, 9(1), 54-57.
- Young, G. J., White, B., Burgess, J. F., Jr., Berlowitz, D., Meterko, M., Guldin, M. R., et al. (2005). Conceptual issues in the design and implementation of pay-for-quality programs. *American Journal of Medical Quality*, 20(3), 144-150.