

Parent-Identified Barriers to Pediatric Health Care: A Process-Oriented Model

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Objective. To further understand barriers to care as experienced by health care consumers, and to demonstrate the importance of conjoining qualitative and quantitative health services research.

Data Sources. Transcripts from focus groups conducted in San Diego with English- and Spanish-speaking parents of children with special health care needs.

Study Design. Participants were asked about the barriers to care they had experienced or perceived, and their strategies for overcoming these barriers. Using elementary anthropological discourse analysis techniques, a process-based conceptual model of the parent experience was devised.

Principal Findings. The analysis revealed a parent-motivated model of barriers to care that enriched our understanding of quantitative findings regarding the population from which the focus group sample was drawn. Parent-identified barriers were grouped into the following six temporally and spatially sequenced categories: necessary skills and prerequisites for gaining access to the system; realizing access once it is gained; front office experiences; interactions with physicians; system arbitrariness and fragmentation; outcomes that affect future interaction with the system. Key to the successful navigation of the system was parents' functional biomedical acculturation; this construct likens the biomedical health services system to a cultural system within which all parents/patients must learn to function competently.

Conclusions. Qualitative analysis of focus group data enabled a deeper understanding of barriers to care—one that went beyond the traditional association of marker variables with poor outcomes (“what”) to reveal an understanding of the processes by which parents experience the health care system (“how,” “why”) and by which disparities may arise. Development of such process-oriented models furthers the provision of patient-centered care and the creation of interventions, programs, and curricula to enhance such care. Qualitative discourse analysis, for example using this project's widely applicable protocol for generating experientially based models, can enhance our knowledge of the parent/patient experience and aid in the development of more powerful conceptualizations of key health care constructs.

Key Words. Barriers to care, access, disparities, patient-provider communication, pediatric cultural competence, qualitative methods

Children's health care services access, utilization, and outcomes in the U.S. are characterized by disparities across vulnerability factors such as socioeconomic status (SES), race/ethnicity, and language (Newacheck, Hughes, and Stoddard 1996; Smedley et al. 2003). While much research has documented the associations between variables such as insurance status, race/ethnicity, education, and English language ability on health care access and quality, less is known about the *processes* by which these associations arise. Qualitative, patient-centered research methods hold great promise for expanding our knowledge in this area.

Building on Andersen and Aday's behavioral model of health care access (Aday and Andersen 1974; Andersen and Aday 1978), Aday's model of vulnerability (Aday 1993, 1994), and the noncategorical approach (Stein et al. 1993) to pediatric quality-of-care measurement, Seid et al. (2003) have proposed a conceptual model to organize examinations of how health care structures and processes affect health-related quality of life for vulnerable children. Earlier versions of this model have been used to generate a parent-report primary care measure (Seid et al. 2001), examine the effects of language, race/ethnicity, and access to care on parents' reports of primary care experience (Seid, Stevens, and Varni 2003), and compare child health services access and primary care experiences on both sides of the U.S.–Mexico border (Seid et al. 2003). However useful for describing relationships between vulnerability factors and access to and quality of care, these quantitative studies fell short in elucidating the processes by which these relationships might arise.

For example, Seid, Stevens, and Varni (2003) documented, in a sample drawn from 18 elementary schools in an urban school district, that insurance status, language, and presence of a regular provider of care were significantly related to scores on a parent-report measure of pediatric primary care experiences called the Parent's Perceptions of Primary Care survey or P3C (Seid et al. 2001). A closer look at these data reveals that more than half (56 percent) of those with the lowest P3C scores (*Z*-scores less than -1.96) were insured, 43.5 percent completed the survey in English, and 39 percent reported having a regular doctor. In other words, despite the significant associations between vulnerability factors (insurance status, language, having a regular source of

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care) and the quality of primary care reported via the P3C score, a substantial number of children *without* these vulnerability markers experienced poor primary care. Conversely, a substantial number of children with vulnerability markers experienced *better* primary care.

Marker Variables and the Processes They Can Mark

This variation implies that insurance status, language, and presence of a regular provider are “marker” variables—variables that assign an individual to categories that mark other sociobehavioral processes. These other processes can be understood to account for the differences seen in the P3C scores.

The Seid et al. (2003) model, revised accordingly to include the construct “barriers to care,” posits that disparities in care and outcomes arise, in part, because barriers to care moderate each child’s journey through the health care services system. Barriers to care are conceptualized as *processes* related to, but distinct from, sociodemographic vulnerability characteristics (Schulman et al. 1995; Committee on Pediatric Research 2000). Thus, every individual may experience barriers to care (Aday 1993), but certain vulnerability characteristics (e.g., race/ethnicity) increase the risk, and effects of, barriers to care.¹ Refocusing from vulnerability factors to barriers to care entails a shift in attention to *process* variables, which provides a way to theoretically link patient experience to quality of care. That is, instead of merely knowing *which* groups are experiencing *what* disparities, by focusing on processes through a qualitative lens, we can begin to know *why* and *how*.

In order to best understand these processes, it is essential to understand the perspective of the patient, or in this case, the parent. The research to be described here attempts to do just that.

Identifying Barriers to Care: The Importance of Parents’ Perceptions

Parents are, increasingly, an important part of the pediatric care team (McMahon, Rimsza, and Bay 1997; Bryan and Burstein 2002; Sobo and Kurtin 2003). They are in a unique position to report on the care their children receive (Crain et al. 1998; Dinkevich, Cunningham, and Crain 1998; Garwick et al. 1998; Homer et al. 1999). And their perceptions and experiences of barriers to care may differ in important ways from those of health care professionals. These differences signify, among other things, the sometimes vast social and cultural gaps that separate parents and health care professionals. Professionals are acculturated to the world of health care, while parents experience this

world (initially at least) as foreign and opaque—as a new and different culture (Sobo and Seid 2003). And parents are in a different social position in relation to this world than professionals. Understanding parents' perceptions, and the ways they might differ from those of health care professionals, is the key to developing programs and interventions to minimize barriers and is central to the provision of patient-centered care.

Maximizing Qualitative Methods for Health Services Research

In this article, we describe the parent experience of seeking care based on findings from Spanish and English language focus groups. We used these groups to gather information on process variables that the marker variables from the school study described above might be marking, and to devise a barriers to care questionnaire (BCQ) to measure their intensity for large populations (Seid et al. 2004).

Focus groups have long been utilized for developing questionnaires (Sudman, Bradburn, and Schwarz 1996). They are also useful for describing the potential range of responses that a given group might have to a particular question, from that group's point of view, and for providing a rich, in-depth understanding of the meaning of those responses so that the reasons behind questionnaire findings, such as frequencies, can be better understood (Basch 1987; Bender and Ewbank 1994).

But much focus group research in health services research (HSR) stops short of this. Overformalized, discussion-limiting moderation processes can yield “equivalently limited data” (Morgan 1997, p. 40). Moreover, despite the existence of powerful qualitative analysis methods (e.g., Glaser and Strauss 1967; Strauss and Corbin 1998; Quinn 2005), much HSR subjects qualitative data to quantitative analyses. To develop questionnaires, many researchers simply code concepts and then sort them by frequency of mention (although this may not represent a concept's salience to a group). Beyond such classic content analyses, some mine transcripts for quotations to exemplify frequently mentioned concepts.²

This article provides a robust example of the type of actionable conceptual model building that can be done with focus group data using *qualitative* analysis techniques—in this case, simple techniques adapted from anthropological discourse analysis for use in applied HSR. Qualitative analysis provides a powerful tool for achieving a more holistic perspective on issues related to health care experiences and quality than quantitative analysis methods can offer, thus enhancing the applicability and utility of HSR.

METHODS

Subjects and Recruitment

Potential focus group subjects were identified through participation in the previously mentioned school-based study (R01 HS 010317). This study, which examined health care access, primary care, and health-related quality of life, surveyed parents at 18 elementary schools in the San Diego Unified School District. Schools were purposively sampled based on the proportion of target-language speakers (Spanish, Vietnamese, and Tagolog) and heterogeneity of SES as measured by percent of the school student body eligible for Federal free or reduced-price lunch programs. At selected schools, classes were randomly selected within grade. As part of the survey parents indicated their primary language and their willingness to be contacted for further research.

The sampling frame for the present project's focus groups, convened in Summer 2002, included parents who reported their child having a chronic health condition, who spoke English or Spanish, and who had consented to further contact ($n = 246$). Children with chronic conditions require more health care than normal and so it was assumed that their parents would be a rich and efficient source of data for understanding and developing strategies for overcoming barriers to care (Garwick et al. 1998).³ The children had a wide variety of chronic conditions; asthma was the most common.

To ensure that parent perspectives were represented regardless of English proficiency, focus group parents were randomly sampled within language (language and other demographic data used to describe the present project's sample were collected as part of the original school-based research). Language groups for the present project were English and Spanish; only about 10 percent of San Diegans cannot speak these languages (Sanchez 2001). Because this part of the project (identifying barriers to care) was generative, no further a priori sampling stratification was done.

The study design called for quota samples of 10 English- and 10 Spanish-speaking adults who were parents (or guardians) of children with chronic health conditions. Given that each parent had extensive experience in health care seeking because of the children's conditions, and given the particular focus group methods that we would use, a sample size of 20 was deemed sufficient both for instrument development and for eliciting the depth of information necessary for descriptive and hypothesis-generating purposes, which do not depend on large numbers for power.

Potential participants were each assigned a random number and contacted in the random number order by telephone, or mail (if no working

number), until quotas were reached. The study was described, and potential participants were invited to participate. In the course of achieving our quota of 10 Spanish- and 10 English-speaking participants, we cumulatively attempted to contact 27 English speakers and 32 Spanish speakers, or 59 of the 246 eligible adults. Of these 59 individuals, 20 (34 percent) had moved, leaving no further contact information. Of the 39 actually contacted, six (15 percent) refused.

We scheduled the 36 consenting individuals for focus group participation, knowing that some would not actually attend. Thirteen (33 percent) never showed up, even with repeat appointments. When 20 (51 percent of those ever actually contacted) had participated, recruitment efforts ended.

Focus Group Processes

Focus groups were conducted by a pair of facilitators (a moderator and a recorder) trained in health promotion and education and in focus group methods. Three focus groups were conducted in each language, for a total of six focus groups. On average the groups each included three participants. Small numbers of participants can be useful in experience-oriented research; smaller groups can yield less normative rhetoric and provide time for more in-depth discussion regarding particular experiences than is possible with large numbers of participants (Morgan 1997).⁴

The groups met for 2-hour sessions, which were audiotaped with participant permission. The focus groups were informal and the moderator was non-directive so as to generate as much experience-based narrative data as possible and encourage “sharing and comparing” (Morgan 1997, p. 21) among the participants (generation of data through the *interaction* of participants is a key feature of focus groups). After informed consent was procured, open-ended discussions focused on (1) families’ experiences in general with the health care system, (2) barriers to access, use, and receipt of quality care, and (3) strategies families have used to overcome these barriers. This “funnel based” forum (Morgan 1997, p. 41), with its broad beginning and narrower ending, allowed for free discussion while ensuring an acceptable degree of comparability across groups. Families were compensated for focus group participation with \$50 in gift certificates.

Data Analysis

A qualitative content analysis protocol designed by the first author was used to analyze the focus group tapes.⁵ While not generally applied in HSR, the various techniques drawn on are commonly used in anthropological discourse analysis for identification, interpretation, and ordering of themes; a review of such techniques is found in Ryan and Bernard (2003). The protocol included

triangulation through the inclusion of multiple researchers (Patton 1999) to offset possible concerns regarding subjective bias. It is described in full in a Web-based appendix to this article.

The form of analysis used for this project goes beyond simply counting (quantifying) terms or phrases. It aims to characterize the variously connected frames of reference that parents use to order their perceptions and understandings of the concepts (in this case, barriers) represented in those terms or phrases. These can be derived by carefully and systematically attending to the narrative contexts in which particular concepts are mentioned (Glaser and Strauss 1967; Bernard 1995; deMunck and Sobo 1998; Strauss and Corbin 1998; Patton 1999; Quinn 2005).

In brief, study staff listened systematically to all focus group tapes and carefully listed all barriers mentioned, bearing in mind the situation-specific contexts in which they were brought up (i.e., the narratives or story lines that they were part of) as well as negative cases or cases in which barriers were surmounted or mitigated. Rather than sorting listed barriers into a priori categories, researchers met together and named potential categories that emerged from their repeated, iterative reviews of the barriers. Category validity was ensured through a team approach in which all research team members individually considered and then together discussed and arrived at consensus regarding barriers and categories, and their definitions. In keeping with the methodological focus on meaning and experience, much discussion centered on the situation-specific contexts in which the various contested barriers were encountered.

In tandem with the category-development process, a process-based, experientially motivated conceptual model of parents' experiences of barriers to care was generated. The model sought to capture the experience of trying to access health care, and so the categories were arranged bearing in mind the temporal sequence of the clinic visit, the basic spatial parameters of the experience, and the cyclical nature of health care utilization. As categories solidified, the model was refined in an iterative and intersubjective process of reflection on the focus group findings (including negative cases) and in which rival hypotheses regarding the connections were proposed.

FINDINGS

The Sample

The sample is described in Table 1, which compares the sample to those eligible but not contacted, those who refused or did not show, and those who

Table 1: Sociodemographic Characteristics of Focus Group Sample, Compared with Sampling pool*

	<i>Focus Group Participants</i>		<i>Eligible Not Contacted</i>		<i>No Show or Refuse</i>		<i>Could Not Contact</i>	
	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>
Respondent language								
English	10	50.0	142	75.9	10	52.6	7	35.0
Spanish	10	50.0	45	24.1	9	47.4	13	65.0
Child race/ethnicity								
Native American	0	0.0	1	0.5	0	0.0	1	5.0
Asian/Pacific Islander	2	10.0	34	18.5	3	15.8	0	0.0
African American	4	20.0	36	19.6	2	10.5	0	0.0
Latino	12	60.0	64	34.8	10	52.6	14	70.0
White	2	10.0	49	26.6	4	21.1	5	25.0
Child insurance status								
Yes	16	80.0	158	85.4	15	78.9	14	70.0
No	4	20.0	27	14.6	4	21.1	6	30.0
Maternal education [†]								
LT high school	5	26.3	53	29.0	10	52.6	9	50.0
HS or some college	14	73.7	77	42.1	8	42.1	7	38.9
College or beyond	0	0.0	53	29.0	1	5.3	2	11.1
Relationship to child								
Mother	16	80.0	158	84.5	16	84.2	20	100.0
Grandmother	2	10.0	5	2.7	1	5.3	0	0.0
Guardian	0	0.0	3	1.6	0	0.0	0	0.0
Father	2	10.0	20	10.7	1	5.3	0	0.0
Grandfather	0	0.0	1	0.5	0	0.0	0	0.0
Other	0	0.0	0	0.0	1	5.3	0	0.0

*Spanish speakers were oversampled for the present project (see text).

[†]For one focus group participant, education information was missing from the sampling pool data set.

could not be contacted. The four groups were similar in terms of the relationship of the survey respondent to the child ($\chi^2(15) = 19.5, p = .192$) and insurance status ($\chi^2(3) = 3.6, p = .31$) (a proxy for access; see Halfon, Inkelas, and Wood 1995). The four groups differed, however, in terms of race/ethnicity ($\chi^2(9) = 22.3, p = .008$), language spoken ($\chi^2(9) = 26.2, p = .002$), and maternal education ($\chi^2(6) = 20.3, p = .002$), because of the quota sampling scheme, in which Spanish speakers were oversampled. That is, those with whom we attempted contact (who fell into the categories of “participants,” “no show or refused,” “could not contact”) were more likely than the “eligible not contacted” group to be Latino or Spanish speaking. Also, those contacted had a lower overall maternal educational attainment (Asians and whites were

more likely, in the sampling pool, to have a college degree or greater; Seid, Stevens, and Varni 2003).⁶

Penetrating, Navigating, and Completing a Journey through the Health Care System

Findings from the BCQ can tell us how many people from what groups encountered which barriers and to what degree. These are important data. But what is the meaning of such quantifications in the everyday lives of respondents? Figure 1 depicts the process-oriented, experientially motivated conceptual model of barriers to care that can inform how analysts might answer this question.

In Figure 1, the barriers categories derived from the focus group transcripts are depicted as fitted against focus group members' expressed understanding of the formal U.S. health care system, which is seen as something that must be penetrated or to which entry must be gained before people can get access to or use system resources. The left-to-right flow of the model reflects the temporal sequence of the clinic visit as parents described it, as well as the basic spatial parameters of the experience. Importantly, it can accommodate the fact that no visit exists in isolation; each visit influences the experience of the next. The major barrier domains that emerge against this ordering are listed in Table 2.

In Figure 1, the formal U.S. clinical health care system occupies the middle rectangle or box. To the left are prerequisites to potential system access: having insurance, documentation (e.g., a social security number or proof of legal residence), money, language skills, and navigational skills, which include knowing the landscape of the system so that one can move through it (Sobo and Seid 2003).⁷ And, as will become clear when the various parts of the system are discussed, the system itself was characterized as arbitrary, fragmented, and not child friendly (this is indicated in the horizontal bar superimposed on the rectangular health system box).

More narrowly encountered barriers are listed in the figure in relation to the parts of the clinical care system in which they are most often found. For example and to begin with, once a child's caregiver starts to try to penetrate the system (middle box), he or she has to negotiate access to a care site, for example by phone, as shown in the column just inside the health system box (under "System Access"). This is often easier said than done: "It's hard getting through. You have to call when you don't have anything else better to do with your time." And "Talking to someone who seems to have some kind of authority is impossible."

Figure 1: Phenomenologically Motivated Model of Parent Experience of Pediatric Care

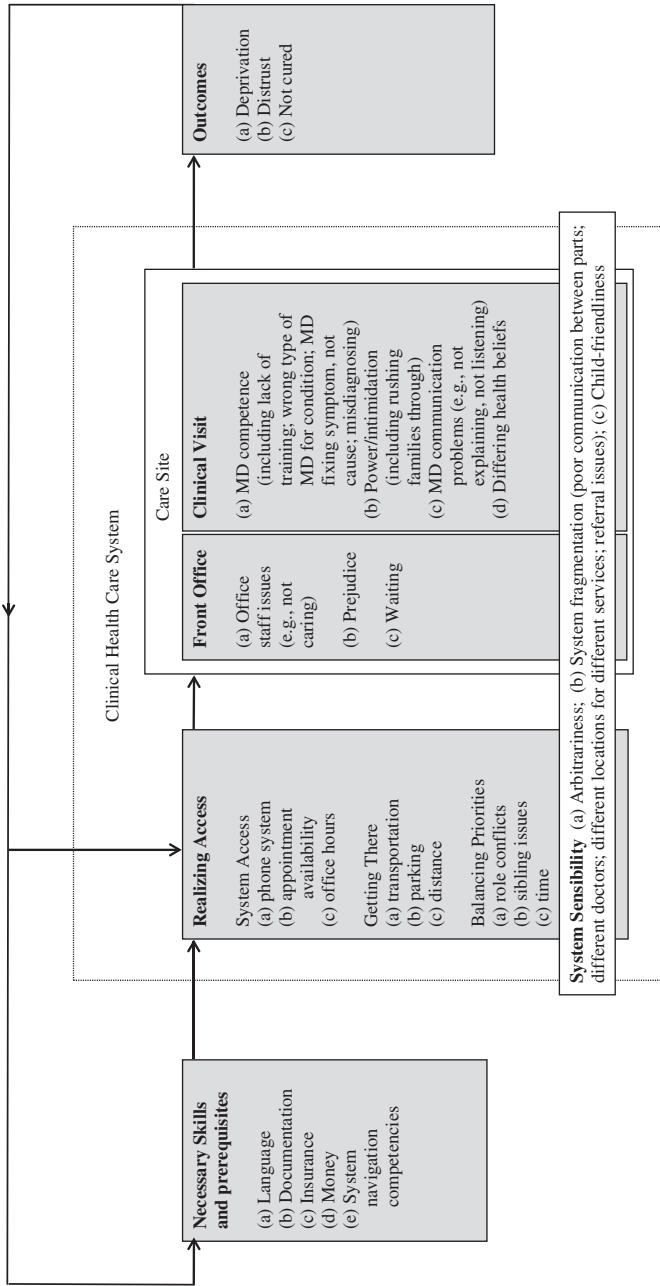


Table 2: Barriers to Care: Principal Parentally Perceived Domains

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1. Necessary skills and prerequisites (for penetrating the formal U.S. health care system)
 2. Realizing access once it is gained (System access; Getting there; Balancing priorities)
 3. Front office experiences
 4. Interactions with physicians
 5. System arbitrariness and fragmentation
 6. Outcomes
-

Phone trees are very discouraging (“Push 1 for Mira Mesa, press 2 for da da da da. Is there a person at the end of this or what?!”). When a call from the health system is expected, “You better be there when they call because if you do call their little extension, you still go through those phone trees.” Sometimes, “the machine tells you it is full, from messages; it can’t receive anymore.”

Questions relative to access go beyond whether one can make contact with the right health care worker by phone. They include (again, as shown in the first column inside the health system box) whether a timely appointment can be secured and whether office hours are compatible with a family’s schedule. Having to wait too many days or weeks was definitely a problem; so were scattered appointments for parents of more than one child or a child with multiple providers.

Once a suitable appointment has been secured, a parent has to get him- or herself and the child to the care site (*Getting There*), which often entails long bus rides with packed lunches. Parents leave extra early, “just in case the bus stops too many times.” Further, a parent has to balance other responsibilities (*Balancing Priorities*), such as to other children, or to a job boss, or to get dinner on the table by a certain time. As one parent said, “The day that I have an appointment to the doctor was the time that I wouldn’t pick up my house, wouldn’t make meals. I would get home [and my husband would ask], ‘So what did you do all day?’ ‘I was with the doctor!’ [laughs].”

A parent who relied on a school lunch program and had multiple children and no after-school care-taking help explained, “I have to take all of them and then I don’t feed them . . . I would have to pay to feed them.” Missed school also could be problematic, although it did mean that other children could be in school while the ill child was being taken to be seen.

Once inside the care site, represented by the larger square on the left side of the clinical health system rectangle, there is the front office to get through (*Front Office*; left side of smaller square). In the front office, parents reported

office staff issues, such as encountering uncaring staff (“They answer you with a rude tone or sometimes they don’t pay attention to you. They pretend that they haven’t heard you”) and overt prejudice. This included socioeconomic prejudice (“The more poor you look, the worse you are treated”), lifestyle prejudice (from a reformed drug user: “They look at who they *think* I am”), and ethno-racial or linguistic prejudice. Rudeness was also encountered in the clinical staff, as the following story, which also contains elements regarding care quality and safety, demonstrates:

They were doing some tests on my girl and I took them [the papers] to the lab and I always tend to look and see if it is the correct name and everything and I noticed that it was the lab work of another girl. So then I went to complain with the nurse and she was not pleased that I had found out this. I told her, “What if you had given my girl another medicine,” and then it seemed that the nurse got upset and she thought that I didn’t speak English and she went to complain with the receptionist. . . . I then understood everything that they were saying. . . . It was ugly how they were talking about me. . . . They. . . . speak Spanish but [are still] racist.

After dealing with reception and initial intake procedures, participants experienced long waiting times, during which, for example, “The sick one is screaming and the well one is screaming because the other one is pulling their hair.” Then, they are left to wait again, with the sick child undressed in a cold examining room, which some think exposes ill children to possible further sickness. And, in the words of one participant, “Then they have the audacity to knock on the door and ask you if you are ready.” Another explains:

The appointment is three o’clock; it’s already three-thirty you are still there on the waiting room . . . forty-five minutes before they call you to go inside. And then they will let you sit there. . . . There is an assistant . . . and then you have to wait again for the doctor . . . another twenty minutes in there. . . . The kid is so sick, he will fall asleep in there already. . . . And then you have to pay extra on parking . . . and they will only look and see your kids for like five, seven minutes.

When finally seen by a doctor (*Physician Visit*; right side of small square in the clinical health care system box), the parents sometimes encountered differing health beliefs or ignorance about health facts because of the context of health system practice. For example:

The doctors say that we should give our children a bath when they have a fever, but I have noticed that in a hospital everything is closed. We have the beliefs about air currents, and the person is going to be bathing the child when there are many air currents in the home, the air comes in, the baby will die.

Parents also dealt with what they saw as inexcusable incompetence:

I'm expecting that [the doctor] is going to check [the boy's] ears, his temperature, I don't know—he doesn't do anything. He looks in and asks how he is doing and I say "The same," then he prescribes another thing. . . . Or they go to their books and start reading, to see what they are going to prescribe, what does he have—If I had a book on my side, then I wouldn't need to come to the doctor.

Parents commonly reported being practiced on, or being treated by doctors who were not trained in the right specialty, or who fixed the symptom but did not deal with the cause. At this point, if not before, parents sometimes (albeit infrequently) packed up their children and left:

I don't know how many things he was asking her, things that are not appropriate. That time I got angry. She felt bad. She goes there like—she had a high fever, she had a headache, she had vomited, it was the time when a virus was going around. That time, I got mad and I left the clinic. . . . If one is not happy, comfortable, what can we do? I'm not going to start arguing with them, I wouldn't win. Simply, if I'm not satisfied, I'm going to leave and not go back.

Not all parents were so immediately assertive. Parents sometimes endured intimidation and communication problems (with doctors not listening and not explaining things). In one story, the doctor "didn't introduce himself . . . had a brusque manner . . . just prescribed medicine not saying what it was for . . . and he was gone." In another, the doctor asked the parent, "'Can't you get [the child] to stop crying?' He is a child. . . . If you don't have the bedside manner to deal with kids or [unclear], you shouldn't be in this business!" Another parent explained how hard it is to listen to instructions and participate in decision making: "The doctor is giving medical attention . . . with a toddler or preschooler for me, you are there and you are, 'Uh-huh, uh-huh' [to doctor]; 'Stop doing that' [to child]; 'Uh-huh'; 'Let go.'"

Another problem was a lack of consistency in doctors: "They don't even let me know that they have changed the doctor, when I'm already inside, an unknown doctor comes in." The lack of consistency was problematic because each physician seemed to start from scratch, and "They don't read the chart, because if they read the chart, they wouldn't ask you the same questions over and over" or "prescribe their own prescription" instead of what the previous doctor had prescribed.

The referral system also proved problematic, as was coordinating information between insurer and provider, and among providers. "They give you one thing and tell the doctors another thing, so I never know" said one participant. Another told of a particular situation in which a referral to an allergist was needed:

My doctor is actually with [Group X] and she. . . . goes to put a referral in and would like to go through a [Group X] doctor 'cause there is communication between the two and [the insurer] will come back and say, "No, you have to go see a [doctor in Group Y]." And they just won't talk. So when I go to the primary care—it's like what happened—I mean, I'm not a doctor. I'll say, "Well, basically they did this." She will ask me questions and it's like—you know, I don't have the answer. And there is no paperwork. I try to get copies of things and [Group Y] is obviously losing their records on their end. So it's like, I go in a circle.

And just getting a referral is hard enough: "It's usually me that has to get on their back and basically say 'come on'", "I had to wait such a long time for him to be approved [for an operation] and the boy used to complain, that his ear hurt a lot and blood would come out of it, out of the ear, and I would take him to the clinic and they would tell me, 'No, until he is approved.'" The problem is not always with the payer, as the following story shows:

We went to—my daughter, she broke her, we didn't know it was broken, she had a sore wrist so somehow we ended up. . . . We didn't get particularly good service. We knew that something was wrong with it, but he wouldn't authorize. . . . When I asked him for a splint, there was nothing.

Throughout the health care journey, which often ended with perceived sub-optimal care leading to a sense of deprivation and distrust ("marginalization"; see Seid et al. 2004; Kreps 1996), parents endured a sense of the system's fragmentation and arbitrariness. In other words, and as represented in the horizontal bar running across the health system box in Figure 1, rules changed from visit to visit ("change like the wind"), fees were inconsistent ("It all depends on who is there"), records were not sent from the lab to the office, referrals were delayed or not forthcoming, and paperwork went missing.

One child sent for an X-ray to an off-site location arrived there only to find that they were closed for the day. Another, according to her parent, "kept having to get multiple blood tests and she hated that—she is only four—getting poked too many times and that is because they lost the records." One caregiver received a prescription for medicine for her asthmatic grandson from a first doctor, only to have the next doctor who saw the boy disagree with the prescription that she had already spent her co-pay money on. She said, "He goes, 'Oh I don't want you to take that medicine.' And he dumps it in the trash. So, if you have a co-pay you then go, 'Oh.' So I learned my lesson."

Access and care site features affect outcomes, but the opposite also can be the case, as shown by the arrow leading back from the outcomes box on the right in Figure 1 to the beginning of the visit chain (left side of figure). A

negative feedback loop can be created when parents experience a sense of relative deprivation, distrust the system, and have their children still not cured. This can underwrite poor adherence and low expectations, and undermine the desire to return to the system for follow-up or repeat visits.

Surmounting Barriers

Barriers could sometimes be mitigated or circumnavigated if encountered. This generally involved learning, and then playing by (or figuring out how to positively manipulate) the rules of the system. (“You have to jump through hoops and you just got to play the system to be able to get what you want.”)

It was true that the arbitrariness noted above, experienced perhaps because of quickly changing or capriciously enforced rules, or disagreement between various parts of the system, could make understanding the rules problematic; however, in some cases it could be done. For example, one participant shared what she had learned regarding asthma inhalers with her focus group: “Always make sure you tell them to put at least two or three on a prescription, so you don’t just go and get one inhaler for ten or twenty dollars which your co-pay is. You can get like three inhalers under the same prescription, so some doctors, you have to tell them that is what you want. They go, ‘Oh, oh I see.’”

Managing to get a direct number for a physician office was a strategy some used to get around the centralized appointing system that one common insurance carrier offered. Similarly, to get to an unlisted extension, one might call a known extension, and “say, ‘Oh, I’m sorry, I was trying to get this department.’ They’ll put you right through. That is how you do it.”

But such “functional acculturation” to the health system (Sobo and Seid 2003) was only something that could be acknowledged by caregivers in hindsight. In other words, with few exceptions (completing paperwork being the primary one), not knowing how to do something was not listed as a barrier to care because people did not know that they did not know how to do that thing until someone else showed them what they could have been doing all along, or they happened on a strategy that advanced their quest for high-quality pediatric care.

“A lot of times,” one parent said, “I’ll kind of go around the receptionist and talk to them in the back. . . . They will tell me what other people have done to get what they needed to get.” And parents sometimes had to “be very, very assertive”; for example, “even getting a referral, it’s usually me that has to get on their back and basically say, ‘Come on.’” One parent related a situation requiring her to “get ugly,” or take loudly assertive action. She said, “You

shouldn't have to do that." But as another noted, "We had to fight so hard for our children."

DISCUSSION

Implications

The conceptual model that we have described represents the experience of the parent trying to access health care for his or her child. It illuminates the findings of the quantitative project that it stems from, enriching our understanding of the fact that, for example, many of those reporting poor primary care experiences belong to groups traditionally thought as having good experiences of primary care. It contributes to the conceptualization and operationalization of the construct of barriers to care described in the introductory section of this article. It furthers the conceptualization of barriers to care as a multidimensional construct, as potentially impacting children's health care at several points in the care process, and as distinct from, yet related to SES and race/ethnicity. Importantly, it addresses, in depth, the processes by which disparities may arise. It thereby supports a more robust, practical, and actionable understanding of the construct of barriers to care.

The model also contributes to the ongoing discussion contrasting the patient experience with patient satisfaction. A distinction has been made between self-reported experiences with health care delivery and ratings of satisfaction with health care delivery (e.g., "How satisfied were you with your wait time?") (Flocke 1997; Starfield et al. 1998). Satisfaction ratings depend upon an individual's *expectations*, such that high satisfaction may result when low expectations are met (Dougall et al. 2000). For example, if one expects to wait 4 hours to be seen, then a 3-hour wait time might be rated as very satisfactory. Therefore, satisfaction research yields few suggestions regarding how the health system can be improved (Starfield et al. 1998). Patient *experiences*, however, can be compared with specific prescriptive criteria (e.g., that wait times be less than 1 hour) (Bindman et al. 1996). As such, criterion deviations can actually index areas for improvement. Parents' experiences of pediatric care, as we have described them here, have many implications then for organizations interested in improving the care experience.

While the stories represented in the model's parts may be very familiar to those working on the front lines of health care, in HSR circles the phrase

“barriers to care” often serves as shorthand for lack of insurance or of English proficiency (but see Friedman 1994; Halfon et al. 1995). Importantly, the experience of low-quality care is not recognized as a barrier to future care because traditional HSR barriers models assume that all care is good care. The model generated through our research questions that assumption.

The model also contributes to the barriers to care debate because it is comprehensive and patient centered. It considers the entire health system. It includes items generated by parents themselves, as opposed to health services researchers, and positions parents as quite capable of being innovative, active care team members, as opposed to passive recipients of care. It shows that lack of health care services background, or low functional biomedical acculturation, is itself a major barrier to maximizing service provision (Sobo and Seid 2003). Further, it considers the *outcomes* of experiencing the barriers noted and shows how they contribute later on to suboptimal use of the system by parents.

Methodological Keys

The model could not have been created without the adoption of a more holistic orientation toward the data than is typical in HSR. This entailed a focus group process designed to garner extensive experience-based narrative data from each participant, a concentrated qualitative data analysis phase, and the inclusion of data collection staff in the analytical endeavor.

All five of the category-development sessions were conducted within a 10-day time period and all investigators were available to concentrate on the process. Immersion in the analytic endeavor is key to the validity and reliability of the products of the data reduction process used. It is crucial that, for this type of analysis, meetings are closely sequenced, time to reflect on meeting discussions and data in between meetings is provided, and researchers are not distracted by other substantive projects or data during the intensive analytic phase.

Qualitative research is not amenable to outsourcing the various components of a project because of the centrality of holism and interpretation to its epistemological basis. This point is paramount. Traditional ethnographically oriented qualitative researchers demand research designs in which *one* researcher conducts *all* study functions. For HSR, at the least, each team member’s participation in the analysis must be informed by actual participation in data collection. No shortcuts can be taken.

Limitations

The model does have limitations. For example, although it accounts for experience with the system and positions each visit as part of a cycle rather than an isolated incident, it does not account for the impact of vulnerability factors such as SES; it therefore cannot show how more vulnerable parents' experiences are in any way different from those of less vulnerable (e.g., wealthy, white) individuals. The difference between, for example, poor and affluent parents' experiences may lie in the quantity⁸ of barriers encountered rather than in what the barriers are to begin with. Encountering more barriers may underwrite *marginalization*, the internalization and personalization of disempowering experiences within the health care system (Kreps 1996). This may be especially so in persons already marginalized by mainstream society because of skin color, language, poverty, gender, or other factors. Marginalization may in turn lead to low adherence and limit interest in pursuing follow-up care, negatively impacting health outcomes. We can also speculate that parents with little bureaucratic experience and little scientific background may feel more marginalized than others by the health care system and therefore may find care barriers particularly daunting.

Secondly, the model cannot represent every parent's actual and specific personal experience. This is normal in studies where findings are aggregated as were ours. Moreover, because the model is a composite, it reflects a general schema inferred from the analysis of all participants' explications and comments. In other words, not all parents had such explicit conceptualizations of the health care system.

A related limitation stems from the fact that we did not use participatory methods in drafting the model. Some of the category labels, such as "navigational skills," are our own; our choice to impose them, and our use of clinic-isolating temporal and spatial frameworks to help organize the categories, reflects our aim to generate a model that has broad health care applications, and that is, accordingly, comprehensible to health care workers.⁹

Having said that, our focus on the parents' perspective may need further translation for actual use in health care settings. That is, because of their experience within the system, health care workers may not be able to see barriers from parents' point of view. Despite ample evidence regarding organizational and provider contributions to disparities in care (van-Ryn and Burke 2000; Smedley et al. 2003; Good et al. 2003), health care workers may hold an occupational bias and exhibit defensiveness rather than empathy. For example, two physicians viewing a first draft of the model pointed to patients' missed

appointments and other forms of perceived nonadherence in defense of some of the practices that parents found problematic, such as overbooking. The limitations of such bias are part of the reason for the present interest in patient-centered care that this research seeks to address.

CONCLUSION

Because of our qualitative approach, findings from the original quantitative study suggesting that traditional marker variables failed to capture substantial variation in primary care experiences were illuminated. Further, the quantitative BCQ generated as part of the research described here (Seid et al. 2004) is a better tool than it otherwise would be.¹⁰ Its questions are more reflective of parent experience than they would have been using traditional (quantitative) content analysis alone. And in future research using the BCQ, the validity of interpretations of BCQ findings can be enhanced through use of the model of parent experience we derived.

Our goal in describing our experientially motivated conceptual model of parent experience is *not* to shift the competency burden to the shoulders of already vulnerable and disenfranchised health care consumers. Rather, it is to raise awareness in the biomedical world of the essential strangeness of the system, and to create a bridge between two worlds—a bridge that can lead to measurable increases in quality of care.

Our focus on parental report also does not imply that the locus for intervention must be at the individual level. Although barriers are encountered on the individual level, they are generated and maintained by, and organized according to, higher-order social structural arrangements (Singer et al. 1992; Loustanaun and Sobo 1997). Although we cannot, in the context of this research, alter macrolevel social structures, we can identify modifiable barriers that have the potential to affect entire patient populations, not just individual families. Hypotheses generated using the model can be tested in future HSR studies.

For example, one popular intervention aimed at increasing patient centeredness and decreasing health disparities is cultural competence training (Brach and Fraser 2000). But as the findings described here show, health care workers are not the only people who need to become competent in cross-cultural exchange. Policies and programs must ensure that patients and families, too, are provided education and assistance so that they can navigate the health care system, which, as anyone who has known or has been a patient knows, is a culture unto its own. The barriers to care model that we have

described can help us to gain insight into (testable) ways to better equip all health care consumers with the cultural competence necessary to navigate the biomedical world (Sobo and Seid 2003).

The information provided in this article will be of value to health care workers, program planners, and policy makers who seek to understand why parents sometimes act in ways that seem, on the surface, nonsensical or counterproductive, and to address parents' needs in a truly patient-centered fashion. Moreover, they will be useful to those who seek to improve parents' experiences of, and thereby change their responses to, the pediatric health care system. Doing so will help to reduce health disparities by increasing each child's likelihood of receiving the highest quality health services available.

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NOTES

1. We define vulnerability to poor health outcomes, after Aday (1993), as an individual's risk for poor physical, psychological, and social health. Vulnerability is often represented by social status (age, sex, race), social capital (family, community), and personal capital (SES, language ability) factors that affect the risk of poor health outcomes (Aday 1993). We would add to this vulnerability as measured by degree of functional acculturation to the biomedical system (Sobo and Seid 2003). Vulnerability has been shown to affect access, continuity, and care coordination (Newacheck, Hughes, and Stoddard 1996).
2. Another problem precedes analysis: many HSR focus groups are highly formalized affairs in which moderators take a very directive approach and rely on highly structured elicitation activities. Participants generally acquiesce to a directive

moderator, keeping silent regarding ideas that do not overtly fit the moderator's data-limiting approach. In addition, formal exercises can occupy much of the focus group's time, eclipsing the time spent in open-ended, interactive discussion among participants.

3. Documented disparities are compounded for children with special health care needs (CSHCN), who use substantially more pediatric health care services than their healthy peers (Newacheck et al. 1998) and account for the majority of pediatric health care costs (Ireys et al. 1997). The importance of timely access to high-quality health care is greater for these children (Newacheck et al. 1996). Yet a substantial minority of CSHCN experience significant barriers to care (Newacheck et al. 1998), in particular to specialty care (Fox, Wicks, and Newacheck 1993; Newacheck et al. 1996).
4. Group size ranged from two (one group) to five participants. Some researchers may call small focus groups "group interviews"; however, as focus group expert David L. Morgan (1997) notes, the term "focus group" should be understood as an umbrella term, designating a "big tent" that can include many variations" (p. 6). Morgan further points out that the purpose of a research project and field constraints are more important than the six to 10 participant rule of thumb in determining ideal group size. Although little empirical research has been done, Morgan endorses smaller groups when participants are highly involved in the topic at hand, and when researchers desire a clear sense of each participant's experiences (p. 42), as in this particular project (Morgan 1997).
5. The protocol was developed when it became clear that a priori (HSR) categories could not accommodate the data.
6. We used maternal education as a proxy for SES, as more educated mothers may be able to access care, communicate, and assert their child's needs more effectively (Heck and Parker 2002).
7. We do not discuss these prerequisites here because our focus is barriers to quality care for those who already have potential access to the health care system.
8. This is something that the quantitative BCQ will measure.
9. Participants' frameworks included other health systems, such as in Tijuana (Mexico), unauthorized allopathic systems or underground clinics encountered in the U.S., and complementary or alternative systems of health care. Further, some discussed hospital inpatient as well as outpatient and ambulatory care (the model focuses on the latter).
10. The BCQ contains questions based on the 27 categories derived from the qualitative analysis. It begins with the following instructions: "Parents often face barriers when trying to get health care for their children. We are interested in the kinds of things that interfere with getting health care for your child(ren). Please rate how much of a problem each of the following is for you."

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SUPPLEMENTARY MATERIAL

The following supplementary material is available for this article online:

APPENDIX S1. Qualitative Content Analysis Protocol for Developing Process-Oriented Models in Health Services Research: Case Example