Title of Project: Managing The Health Needs of Vulnerable Children

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Structured Abstract

Purpose: This project applied qualitative methods to gain insight into the experiences of vulnerable children's families: how they define their children's health needs, decisions regarding where and when to seek care, and their experiences with care received.

Scope: Vulnerable children in San Diego: 22 families, selected from a subsample of children with poor primary care scores in a larger study (HS10317)

Methods: Data were gathered using in-depth, semi-structured interviews and analyzed using a rapid ethnographic assessment approach.

Results: Parents defined a healthy child as active, happy, energetic, and with a good appetite. They emphasized good nutrition, exercise, and culturally mediated practice, such as regulating heat and cold as ways to prevent illness. Parents tended to seek medical care as a last resort after trying to treat symptoms themselves. They received much of their information from family and friends and used complementary or alternative medicine and home remedies fairly frequently. There was much frustration with wait times and access. Parents want doctors to explain clearly, be thorough, listen, and be a partner. Several parents shared stories of doctors who went above and beyond in their duties.

Key Words: Qualitative research; children; access to care; vulnerability; quality of care

Purpose

Disparities in health and healthcare are a key focus of US health services research. There is a growing recognition of disparities in access to appropriate and timely care for children. Given the high rates of uninsured eligible children, documentation of disparities in health and healthcare across race/ethnicity, and acknowledged gaps between evidence-based standards and practice, increased understanding of vulnerable families' healthcare experiences is critical.

The goal of this developmental research was to collect qualitative information in order to generate hypotheses about how the health needs of vulnerable children are met. The aim of the study was to better understand the ways that vulnerable families manage their children's health needs. Specifically, the study focused on how caregivers (parents) in vulnerable families define their children's health needs, make decisions regarding seeking care, and experience the care received.

Although considerable research has documented the relationship between vulnerability factors and healthcare processes and outcomes, our knowledge of the mechanisms underlying these disparities is less robust. Insight into these families' experiences will afford an appreciation of their decisions regarding care seeking and help define ways that the healthcare system could become more responsive to the needs of the most vulnerable segments of society.

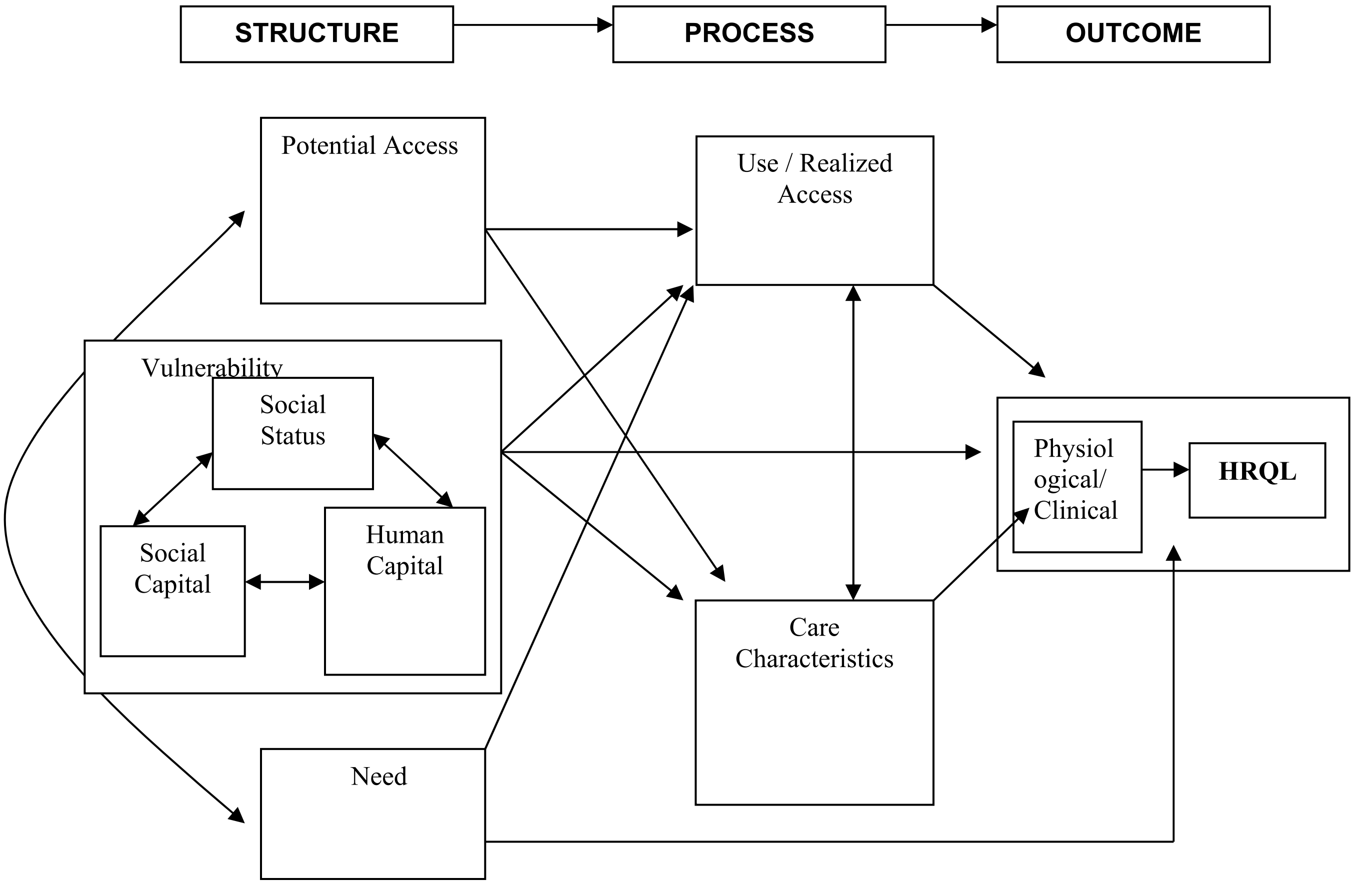
Scope (Background, Context, Settings, Participants, Incidence, Prevalence)

Research continues to demonstrate disparities in healthcare and health outcomes across groups of children defined by sociodemographic variables as vulnerable, and eliminating these disparities is a major priority of US public health strategy. Despite extensive documentation of these issues, less is known about the mechanisms underlying these phenomena. Several limitations exist in the literature. First, there is a lack of understanding of the inter- and intra-personal processes that inform parents' choices when negotiating the healthcare system. Second, the vast majority of the literature approaches this issue from a quantitative, nomothetic perspective, which limits understanding of the mechanisms linking markers of vulnerability with indicators of access and quality of care.

A model for organizing research into how families of vulnerable children interact with the healthcare system has been proposed. The model, shown below is adapted from Seid et al (Seid, Varni et al. 2000) and is framed in terms of Donabedian's model of structure, process, and outcome (Donabedian 1966; Donabedian 1988). Within this framework, the model borrows from Anderson and Aday's behavioral model of healthcare access (Aday and Andersen 1974; Andersen and Aday 1978), Aday's model of vulnerability (Aday 1993; Aday 1994), and the non-categorical approach to pediatric quality of care measurement (Seid, Varni et al. 2000). Specifically, this model is used to frame the approach to data gathering and analyses regarding how caregivers (parents) in vulnerable families define their children's health needs, make decisions regarding seeking care, and experience the care received.

This project grew out of another, larger study, AHRQ RO1 HS10317, "Measuring quality of care for vulnerable children." That longitudinal cohort survey study examined the links among vulnerability factors, healthcare, and health-related quality of life for 3,406 school children from 18 elementary schools in San Diego. Participants were English-, Spanish-, Tagalog-, or Vietnamese-speaking San Diego Unified School District students in grades K through 6 and their parent or guardians.

Conceptual Model for Programmatic Research into Quality of Care and HRQL for Vulnerable Children



Methods (Study Design, Data Sources/Collection, Interventions, Measures, Limitations)

Participants were recruited from the larger HS10317 sample based on parent reports of primary care; parents reporting the worst primary care experiences are considered, de facto, to be vulnerable to receiving poor healthcare. Primary care quality was operationalized via the "Parent's Perceptions of Primary Care measure" (P3C), a brief measure of parents' reports of pediatric primary care experiences, developed and validated as part of HS10317 (Seid, Varni, et al., 2001). The P3C measures parents' reports of primary care characteristics that, when present, define good-quality primary care. In order to identify a sub-sample defined by poor primary care for the proposed project, the sample was divided into two groups based on standardized P3C scores. Standardized scores greater than –1.96 were classified as "better care," and standardized scores less than –1.96 (N =147, 4.3% of the sample) were classified as "worse care."

There were three consecutive, face-to-face, open-ended interviews with each participant. The content or focus of each interview is outlined in the table, which also summarizes all participant contact points in a linear fashion. By spreading the interviews over time, both interviewers and interviewees will be afforded time to reflect upon previous conversations so that each meeting will enable them to build on the last. Furthermore, this arrangement will enable building the mutual trust necessary to elicit from interviewees a truer depiction of their beliefs, attitudes, and experiences.

Table. Contact points and purposes: Interview schedule and content guide

	Telephone Call	**First Interview**	**Second Interview**	**Third interview**
	Recruitment (6 minutes)	*Defining Health Needs (1 hour)*	*Use of services to meet perceived needs (1 hour)*	*Forgone care; Definition of good healthcare (1 hour)*
Content	Screening for inclusion Verbal consent Address verification Set first interview appointment	Procure consent Background information check Specific and general attitudes and beliefs about health and disease Health improvement strategies and practices	What services are used; where, when, why Caregiver participation in care decisions Use of self-help, alternative medicine, home remedies	When is care foregone; how? Why? With what consequences? Ideals for health services: functions, locations, needs to be met, etc.

Interviews took place in the participant's home. This provided interviewers the opportunity to observe the environment in which the family is attempting to function. Within 3 hours of each interview's end, setting and situational notes were recorded. These notes, which refer to observations not reflected in the audio recording, were used to supplement, clarify, or qualify the transcribed narrative data when necessary.

The interviews were audio taped, transcribed, and translated. Transcripts were reviewed repeatedly, and a coding scheme was developed to identify major themes of interest. In keeping with standard ethnographic or qualitative methodology, most of the codes were derived from the data itself rather than pre-determined. However, some of the codes captured responses dealing with issues identified in the literature as salient, such as forgone care.

Results (Principal Findings, Outcomes, Discussion, Conclusions, Significance, Implications)

Twenty-two sets of interviews were completed (10 English speaking and 12 Spanish speaking). Themes emerged from the interviews, as described below.

Defining healthcare needs and deciding when to seek care

Parents defined a healthy child as one that is active, happy, and energetic and has a good appetite. In contrast, they know that they have a sick child when he/she is lethargic, tired or quiet or won't eat.

Parents try to keep their child healthy by maintaining a healthy diet and, to a lesser extent, making sure the child has adequate exercise. Several parents also talked about proper clothing (e.g., making sure their children wear jackets/sweaters) and other culturally mediated practices to regulate heat or cold (e.g., don't let them walk in bare feet on the cold floor).

> "Every time they take a shower at 10pm or midnight, they get sick… Have to take a shower in the morning or afternoon, but not night time… Cause you know in the Philippines, they didn't take a shower at night….that's the way [it was] always done."

> "[I just do the] regular mom thing. I make sure they have a sweater and jacket every morning and they're always bundled up."

For the most part and to the greatest extent possible, parents try and prefer to treat their children at home before turning to the doctor or ED.

> "I give them kind of what I know they (the doctors) are going to tell me to give them and I see that they don't get better. That is when I call."

Parents get much of their information from family and friends, and knowledge and practices are often passed down through the generations (e.g., that's what my mother did when I was a kid).

> " I have a nurse who luckily that I can talk to at work, like when my daughter was sick. I would say, 'What do you guys think?' and they told me to ride it out for 2 days and then if it doesn't go away, to take here [to the doctor]. So I do get advice from them, but it'd be better if I could take her into a doctor and call them and have someone that knows her history" (from a mother whose child was uninsured).

The use of complementary/alternative medicine or home remedies was also fairly frequent.

> "Last time my son sick, but it's on the weekend so I didn't take him to see the doctor….I cook the [Chinese] herbs for him and stop the fever and coughing….If the herbs…don't work, I will go to see the doctor" (from a Chinese mother who uses Chinese herbs and other practices learned from her family).

> "One time [my daughter] wouldn't stop crying for almost about a week or so and we couldn't figure out what was going on with her and come to find out this lady (a Philippine healer said she had a bad cramp in her leg, or a big knot in her leg

> and she (the healer) was just rubbing the leg out… and next thing you know, she was out running, she was playing."

Experiences with care

Parents talked about their frustration with wait times and the inability to get an appointment right away.

> "When we got to the hospital, we sat there for a long time, when they took us back there and took her temperature it was like 98 or something and she's like, 'Okay, well go sit back there.' We were out there for like another hour and [my daughter's] like, 'Mommy, let's just go home.'….So, we ended up going home before we saw the doctor. And I went and told the lady that we were just going to go home and stuff and she was all, 'Okay.'"

> "I don't like to go [to the ER] because when you go there you spend a long time and it doesn't help a lot."

> "You sit for 2, 3 hours waiting to get in. I mean I got to the point and I asked them, 'Why are you scheduling appointments? Why are you even bothering to schedule appointments?'"

Parents want doctors to explain thing to them and help them understand what's going on with their child – they want to be told what's wrong and what will fix it: they don't like uncertainty or delays in diagnosis.

> "When my daughter was at a hospital…the doctors there would take time to explain to me, this is what is going on…they were serious, but at least they explained to me, as a mom, because I was concerned about my child… Cause when nobody talks to you, you don't know what is going on and you think the worst."

> "[Doctors] should talk to their patients about what's wrong…explain things to them and what kind of medication."

> "Take a few extra minutes to make sure that your patient understands what you're saying and you communicate to each other….part of the whole problem is lack of communication….I am not about to let you just push me in there and say something and send me on my way. Because I, myself, have had the experience of being prescribed the wrong medication."

Parents want their child's doctor to be more thorough – rather than taking a cursory and isolated look at the presenting problem (e.g., ears, cough) and simply writing a prescription to provide a quick fix, they want doctors to thoroughly examine the child and delve deeper to identify the possible underlying cause behind a problem.

> “She was full of spots. But [the doctor] did not check her skin. She only looked at her ears, mouth…and that was it….You can do something in 5 minutes, but somewhat a little better, no?”
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> “Maybe that is why we have more faith in doctors in Mexico. Because they give us a check-up even if you are not going in for a physical exam…they take their time to exam you….the doctor will check your ears, your heartbeat, your throat…even if you go their with another problem.”
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> “They don’t do anything….they put a Band-Aid on whatever is the problem, they don’t try to find out the root of the stuff….They are not thorough anymore….Because they are too rushed. They want to…get it over with you and go to the next person.”

Parents want continuity in their child’s healthcare. They want to have a partnership with their child’s doctor. And they want doctors to listen to them.

> “A long time ago, used to have a family doctor that your whole family will go to…have that relationship with them….will know the family history…have experience with my family and be comfortable….They will know you better than [a doctor] that just came yesterday…I don’t know if that’s possible, the way things are changing now.”
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> “It was step by step of [the doctor] going through the things that he needs me to go through and me following through with the things. So kind of working hand in hand on making sure that we follow up on what was going on with her, medicine wise and all that.”
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> “The doctor should be my partner in keeping my children healthy because they practice medicine and the parent is here all the time watching the kids.”
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> “The way he talked to me, he would not answer my questions…he thought I was never going to school to be a doctor, so how would I know?…. I’m the doctor, I am telling you this is what is going to happen and this is how it’s going to be.”
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> “She cares, she listens to you….She doesn’t treat you like this is my 15 minutes….She wants to know. She asks you questions, she tells you what to expect if there is anything she is giving to your children.”
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> “She sat and she talked to [my son]. She asked him questions, it wasn’t like we were on an assembly line…like okay, I’m looking at my clock, I’ve got 15 minutes….She’s talking to me not only on a professional level, but as a parent as well….We shared a conversation.”

Several parents shared stories of doctors who went above and beyond the call of duty to make sure that their child received needed healthcare.

> "There were some bills that the hospital said [Medicaid] refused to pay….But I didn't have to do the fighting with them because Dr. C--- said 'don't concern yourself about that. She said 'just concern yourself with taking care of [your daughter]…. She is the best doctor I have ever met in my life….I still call her today when I need any questions for my kids."
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> [Relaying a story where she took her daughter to the ER at night but had to wait a long time, did not get treated, and the daughter was still sick the next day, so she went to her doctor:] "She took one look at her, she said, 'You know what, she needs to go to the hospital.' She said, 'How did they let you out of the Emergency Room?' And she called C--- Hospital, got a couple of doctors there, and she drove me with her car….And stayed there until all the doctors…came to look at her….She had meningitis…If it wasn't for that lady taking my daughter to the hospital as soon as she did, I don't think she would have survived."

List of Publications and Products

The following publication was supported by a different grant, but the kernel of the idea was based on the work from this project:

Sobo, EJ & Seid, M (2003). Cultural issues in health services delivery: What kind of 'competence' is needed and from whom?. Annals of Behavioral Science and Medical Education 9(2), 97-100.

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