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Diagnosis versus Dialogue: Oral Testimony and the Study of Pediatric Pain*

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Abstract: Through the perspectives of the children, this essay examines the communication between pediatric pain patients and their doctors. Based upon the oral history responses of thirty-two patients with chronic pain present for evaluation at the Pediatric Pain Clinic at UCLA, oral testimony was employed to uncover a wide range of topics related to a child's experience with pain such as family dynamics, how and when pain became a life-changing factor, coping strategies, and external sources that contribute to the child's understanding of pain. Most important, children were encouraged to explain what it was like to be in pain, not only to describe symptoms but also to share their dreams and hopes, their fears and uncertainties—as well as the place of pain in their world.

Keywords: children, doctors, oral testimony, pain, qualitative research

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Oral testimony has found its place within the discipline of history and has become an invaluable source for historical data collection and explanation. Projects such as the Survivors of the Shoah Visual History Foundation, Columbia University's multiple September 11 Oral History Projects, and the Oral History of Human Genetics Project at UCLA Center for Society and Genetics attest to the range of

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subjects where oral testimony has contributed to our knowledge and understanding not only of the past but also of the present.

Oral history has recently entered wholly new fields, including clinical medicine and medical anthropology. Spurred by the burgeoning literature on medicine and narrative by such writers as Arthur Kleinman, Arthur Frank, Rita Charon, and David Morris, oral testimony is increasingly viewed as a potentially valuable source for understanding the experiential aspect of illness.¹ At a recent (2006) meeting of the International Society for the Study of Pediatric Pain, for example, studies that incorporated oral testimony to elicit the experiences of children in a hospice and the experiences of children with cancer were presented to an audience of mainly doctors. Information about the patient's coping strategies, assessment of treatment plans, and moods are some of the items elicited through oral testimony. Health care professionals are beginning to see that the medical chart is only a small part of the story of the patient's illness.

Communication between adult patients and their physicians has been an area of study for several decades.² By contrast, children's perspective on health care and communication is a largely understudied topic. The literature is typically conceptual, focusing on the need to listen to children.³ Several studies utilize oral testimony to elicit the experience of illness but none focus explicitly on chronic pain.⁴ To date, no study addresses how health professionals can negotiate more effectively between the child's experience of chronic pain and the doctor's biomedical orientation or offer practical steps that might alleviate the child's suffering and provide a sense of well-being.

One of the most innovative uses of oral testimony in a clinical setting is currently underway at the UCLA Pediatric Pain Clinic, where the methodology is utilized to study the experience of children with chronic pain. The interviews are part of a larger multidisciplinary project entitled "Anxiety, Pain, and Self-Efficacy in Children." Funded by the National Institute of Mental Health (NIMH), the project brings together scholars and researchers from pediatrics, psychology, history, anthropology, sociology, and linguistics. The project's quantitative component utilizes standardized measures to get at a variety of data about the children's physical and emotional health, functioning, attitudes, and opinions regarding treatment. One qualitative component looks at physician-patient interactions during the initial intake at the UCLA Pediatric Pain Clinic using conversational analysis of the videotaped appointment. Hypothesizing that children would be willing to share their experience with pain, the other qualitative component utilizes oral testimony—the children's own words—to uncover a wide range of topics related to children's experience with pain such as family dynamics, how and when pain became a life-changing factor, coping strategies, and external sources that contributed to their understanding of pain, the nature of their communication with doctors, and their expectations about outcomes. Children were encouraged to go beyond a description of symptoms and to share their dreams and hopes, their fears and uncertainties, as well as the place of pain in their world.

Oral history also complements a research methodology used by the oral historians in this study known as grounded theory. Developed by sociologists Barney Glaser and Anselm Strauss, grounded theory is an inductive procedure for deriving meaning from data. The data are elicited from the narrative, that is, it is "grounded in" the

narrative itself. In the qualitative method, segments of data are constantly compared with one another to uncover similarities and differences. The overall object of the analysis is to find patterns in the narrative.⁵

Background

Children with chronic or recurrent pain are among the estimated 12–18 percent of American children who have special health care needs beyond the normal childhood maladies. Despite the large number of children with chronic pain, health care providers as well as primary caregivers do not have an adequate understanding of the child's experience of pain. By understanding the subjective experience, health care professionals and caretakers could learn about factors beyond the physical that influence the child's pain.⁶

An important objective for the project was to find patterns in the children's accounts that would be of interest to health care professionals who work with pediatric patients as well as to medical anthropologists who attempt to understand the role of culture, gender, and the like, on illness. Beyond what researchers and scholars learn, the oral testimony of children in pain provides an insight into an experience we usually do not associate with children. Under normal circumstances, we expect that children interact with doctors only for predictable childhood illnesses. The testimonies of children with chronic pain, however, are accounts of the struggle to adapt to an unexpected situation. They are also accounts of the child's challenge to make sense of a condition that may very well never completely go away. These often lead to personal conversations about the deeper significance of pain in their lives. Finally, the testimonies allow the children to talk about their experience with adults, including doctors, who are looked upon as having special insight into the mysterious malady with which the child lives.

A significant area of interest was the children's experiences with doctors prior to their evaluation at the Pediatric Pain Clinic because children and their parents looked to doctors for answers and help. The team asked the children to recollect and to describe their doctor visits. At issue was the extent to which the children understood what was happening during those visits, the extent of compliance with the doctor's recommendations, and the children's opinion as to whether or not they received the help they sought. This essay focuses on this last topic—what children say about their relationship with their doctors—to illustrate how oral testimony uncovers the dynamics of a critical relationship for patients who visit doctors with greater frequency than the general population. Such information can serve as a valuable source for improving the communication between health care providers and their patients and lead to better informed clinical decisions.

Twenty-four girls and eight boys, ages ten to eighteen (mean age was fourteen years), were interviewed for this project. Twenty-two were Caucasian, five were Latino, four Asian, and one was African American. They reported pain in the following sites (several patients reported more than one site): headache, abdominal pain, back pain, hand pain, foot pain, and facial pain. Four patients reported total body pain. The duration of pain ranged from one month to "all my life"; the average

duration of pain was almost fifty months, and the average number of doctors seen prior to being evaluated at the UCLA Pediatric Pain Clinic was eight.

One-on-one interviews were conducted and recorded by camcorder in the child's home by graduate and postgraduate students trained in oral history methodology. Interviewers used a semistructured format with a flexible script outlining the topics of interest that were identified by the project's oral historians. The backgrounds of the two lead oral historians were, respectively, in trauma narratives and the history of medicine. Interviewers were encouraged to ask follow-up or probing questions outside the script when appropriate. The interviews lasted approximately one to two hours.

The interviews were copied onto DVDs and transcribed and coded using QSR N*6 software. Because no vocabulary exists to describe a collection of interviews with chronic pain patients, it was necessary for the team to create its own controlled vocabulary (indexing terms) extracted from the clinical literature available and based on the children's responses. The controlled vocabulary using QSR N*6 software permitted the team to add, delete, or edit terms and to record the definitions of terms.

Separate orientations/separate vocabularies

The testimonies reveal a serious breakdown in communication between pediatric chronic pain patients and their doctors. In effect, children complain that doctors ignore the experiential component of pain or the child's lived experience. As a result, children are skeptical about the ability of doctors to help them. In the words of one child, doctors "just come up with a routine ... and throw it at you ... and claim that it will solve everything." What accounts for this breakdown?

The oral testimonies of children in chronic pain suggest that children and their doctors have two separate orientations toward pain and employ two separate vocabularies to describe pain that are inescapably linked to these orientations. These orientations may not be full scale, formal explanatory models. Rather, they appear as tacit and embedded approaches to disease and illness. The physician's orientation is biomedical: his goal is to identify and treat a definable medical condition. Once the condition is identified, the physician sees his role as instructive and directive. He tells the child what to do to alleviate the condition. By contrast, the child's orientation focuses on the *experience* of pain. This is a perspective that goes beyond the boundaries of any identifiable medical condition. The child utilizes a language that is primarily emotive. It serves to communicate emotions that are keenly felt and that demand an acknowledging or empathetic response from the doctor.

In the testimony below, a teenage girl wonders what it might be like to live with pain all her life, illustrating the emphasis on the experiential:

Q: If you could share a couple of things about your pain that you haven't shared with the doctors, what would you say?

PATIENT: Hmm. I guess I've shared different things with all of them, but there have been things that haven't come up. I really haven't told them all of the things that I've been telling you about like how I feel about growing up with

this much pain. I think the therapist asked me something about how it feels—why I want to commit suicide. As far as I told him it was basically like, oh, well, you know, all teenagers think about stuff like that. But I mean, I think about things like my life, or like my lifespan, in terms of pain a lot, but I don't really tell them how I feel about getting older and the way this is going. At the point when I had most of those doctors, it was more like, oh, well, you're still so young, this can heal, and things like that. So I don't see it moving forward.

Social psychologist Alan Radley notes that “When people tell stories about their illness they are doing more than recounting a series of events concerning their lives or their treatment for disease. In the course of telling about their situation they are also showing what it is like to suffer.”⁷ In a similar vein, medical anthropologist Isabelle Baszanger writes that communication between an adult patient and doctor are “moments for talking about many different things, ranging from complaints about the body to personal, family, or work-related difficulties. Whether or not to listen to this information and understand and use it as data and how are decisions that require more than just applying theoretical knowledge.”⁸ In the testimony quoted, the patient hints at a patronizing reply (“oh, well, you're still young, this can heal ...”) when she would rather the doctor address the possibility of living with chronic pain. Many testimonies reveal that the emphasis on conditions and diagnosis—the language and orientation of biomedicine—appears to signal to the child that his or her experience of pain and the emotions associated with living with chronic pain are not of any particular interest to the doctor.

The drive toward diagnosis is part of a larger biomedical paradigm shift to “the clinical gaze” that Michel Foucault traced in *The Birth of the Clinic*.⁹ According to Foucault, the dominant discourse in medicine since at least the invention of the stethoscope (officially accepted by the medical profession in 1819), followed by the X-ray (1895), and in the twentieth century the computerized axial tomography scan, magnetic resonance imaging, and other viewing technology has served to objectify the body. The body is transformed into an artifact, allowing it to be reproduced as an image, worked on, parts interchanged, and repaired. One of the consequences of this objectified clinical gaze is to devalue the patient's narrative. As David Morris puts it: “What is the matter?” contains an implicit invitation to talk: a brief or extended story is likely to follow. ‘Where does it hurt?’ pre-empts story-telling. You can point to the spot. No words are needed.”¹⁰ Diagnosis contains and names the experience, transforming it from a personal and subjective experience to a biomedical symptom that is supposed to somehow be objectively “there.” Unfortunately, the search for a diagnosis often becomes the child's total experience with the doctor.

Byron Good showed that clinicians edit (or privilege) elements of their patient's story that are regarded as irrelevant to a clinical decision.¹¹ The child, however, wants the doctor to be attentive to information that may not be discernibly or explicitly clinical. In the following passage, the child utilizes a highly coded narrative (note the repeated use of the words “pay attention” and “detail”) to make a point about the doctor's search for a diagnosis and solution for her pain:

Q: What makes a good doctor?

PATIENT: Attention and wanting to find the cause, not just a fix-it solution right away. Attention to detail, I guess ...

Q: And conversely, what makes a bad doctor?

PATIENT: Someone who just has come up with a routine and wants to just throw it at you and claims that it'll solve everything. A lack of attention.

Q: If a doctor asked you for advice, what advice would you give about treating a young person in pain, to a doctor?

PATIENT: I don't know. Pay attention, I guess, or be detailed.

The child addresses her need for a doctor who is attentive to a greater range of factors besides causes and symptoms. She wants the doctor to "pay attention" and talk about "details"—the lived experience of pain that lies between a strictly physical explanation and a strictly psychological explanation.

Unfortunately, directions are often all that a child remembers about a visit to the doctor. When asked what a doctor *told him* about his pain, a thirteen-year-old boy replied by describing what the doctor *did* about the pain. The boy recalls the directives about his chronic pain but says nothing about what thoughts about the pain the doctor might have communicated to him:

Q: So you've been seeing that doctor for how long?

PATIENT: Four years, four or five years.

Q: What does he say about your pain?

PATIENT: He gave me an MRI. He put me on two different medications. I was on Elavil and now I'm on Topamax.

Patients who visit doctors with complaints want their doctor to take some action. But chronic or recurrent pain often does not respond to biomedical action, and children who have not had success with treatment quickly understand this unfortunate reality:

Q: In your experience, what's the most difficult thing in dealing with doctors?

PATIENT: They get frustrating. I mean they get annoying. They would tell you one thing, and then that isn't helping and you go back, and they tell you a different thing. Doesn't help. It just gets really different.

Physicians certainly have a responsibility to try and reach a diagnosis. But children may find the search for a diagnosis frustrating and entirely beside the point:

Q: Has anybody given you a diagnosis?

PATIENT: No. I mean, some doctors say its tension-type headaches, some say its migraines. So, I don't know. I've never been diagnosed the same thing. I mean, it's headache, but I guess their definitions differ.

Q: Does that scare you?

PATIENT: I guess it does sometimes. It doesn't really because I guess a headache's a headache's a headache.

For the child, the search for a diagnosis, requiring numerous tests that turn out to be inconclusive, soon appears to be a game of trial and error. When the physician cannot

find a diagnosis or a cause for the pain, and refers the child to yet another specialist, the child concludes that the physician has simply run out of ideas. The child does not impugn the doctor's effort to find a cause for the pain; rather, she perceives the doctor's interventions as limited, inflexible, and finally just plain inadequate:

I've been told I have chronic fatigue, chronic EBV [Epstein-Barr Virus], I'm depressed, I have tension headaches. I had a bunch of Lyme tests. One turned out almost positive, just about positive, just on the borderline and the others turned out completely negative, so we went to a Lyme specialist when we were on vacation and he said no I've been told I have a lot of different things. It's funny because each doctor describes it and names it according to his specialty. So if you take the gist of what they're saying, then it's all exactly the same thing, and it's all hypothesis, it's all the first time they've seen it.

In our interviews, children report that doctors mechanically apply a treatment template that, though based upon the medical provider's particular specialty, fails to address the specificity and the uniqueness of the patient's experience:

I felt kind of frustrated because it's so hard to communicate. I always felt like sometimes they'd just go, oh, you know, I went through the same thing, or like, oh, I have patients who have similar problems, but I never felt like that was true. You know what I mean? I never felt like they really fully understood to the point where they—they'd always relate me to other patients, and I'd feel like I didn't have the same problem that they had dealt with.

Each visit for the child seems unrelated to the previous visit—a series of unconnected experiences in which the pain story has to be continually retold. This lack of treatment continuity is disruptive and frustrates the child:

So I went to the doctor. He had no idea. I had X-rays of my head, CAT scans, MRIs. I had—what's the egg thing for your brainwaves or something? I don't know. I had all sort of things. We went to headache specialists. We went to lots and lots and lots of doctors. But they didn't know. They all said that I had the most sensitive headache they'd ever seen before. Because just barely touching, even just holding your hand over my head, it makes it worse, just the pressure of that air. Finally they just ran out of ideas. Then we talked to some people, and they're like, "Do you think it could be chronic fatigue syndrome?" Because actually one of the people at my club has it. So we went to go see a doctor, and he's like, "Well, it's only been three months. It looks exactly like chronic fatigue syndrome, but we can't diagnose you till six months." That was a chronic fatigue doctor. Well, he has done work with chronic fatigue people. He wanted me to do physical therapy so I did that. Then we went to another doctor, and he had a totally different hypothesis as to what it was.

The following testimony ends on a sad note, as the child describes the medical failure not as the inability to provide a diagnosis but as the inability to provide help: "I've seen enough doctors that somebody should have been able to help me. It kind of makes me wonder why I'm not better already. I mean, it's been six months. That's a long time to be lonely and frightened." Loneliness and fear describe the patient's broader experience with her chronic pain, but they also allude to a common childhood byproduct of illness that pain specialists have not successfully addressed.

Pediatric chronic pain patients leave the doctor's office feeling neither wiser nor better than when they arrived:

Q: Did the treatments work to any degree?

PATIENT: No. That's one of the things that bothered me about so many doctors. They've got such a program so not specific to my problem. It's just a set of things to do.

For the child, doctors appear more focused on "a set of things to do" rather than on the problem of pain. When these interventions fail, many children reasonably suppose that doctors have nothing to offer except yet another worthless test or drug. By the time children arrive at a pain management clinic, many have lost the hope that they will be cured or healed.

What oral testimonies teach us about the world of children in pain

"Facts known only by physicians need to be supplemented by values known only by patients," writes physician Mark Sullivan.¹² The oral testimonies revealed an important perception among a small group of children in chronic pain, namely, that doctors do not consider or care about patient values. This disconnect is due to two related factors. First, the physician's biomedical orientation emphasizes diagnosis over the larger experiential component of pain. Second, the difference in focus is clearly conveyed in the language used by both doctor and patient. The doctor employs language whose function is primarily informative and directive. By contrast, the child utilizes language that is expressive, subjective, and experiential. Whereas the doctor's language expects compliance, the child's language expects response. "The challenge," states physician Ronald Epstein, "is to name the illness in a way that is meaningful to patient and physician, wherein the patient's experience of illness is validated and accepted untransformed, and then later reconciled with the physician's diagnostic categories."¹³

The oral testimonies reveal that pediatric pain patients seek more than pain relief. They are concerned with the quality of their life. While relief is undeniably an ethical imperative and the main reason why patients initially seek medical advice, there is a point at which the child refocuses the experience of pain to emphasize the loss (or feared loss) of function. If no biomedical action or prescription on the physician's part is going to "cure" the patient, then the critical issue in chronic pain management has to be how to help the child function so that he or she can enjoy a satisfactory quality of life.

Medical ethicists, when discussing decision making in a clinical context, have long addressed quality of life.¹⁴ These discussions raise the larger question of what constitutes health and illness, leading to patient-centered assessments of what truly matters when doctors discuss possible treatment options. Recent work by pain specialists has embraced value-laden, subjective, and experiential aspects of illness: "Once we accept that health status must be evaluated for a particular perspective, then we must decide what perspective is authoritative and why. The answer to the

“why” question will help us decide how thoroughly patient values must be included in our outcome measure.”¹⁵

Our study did not address whether or not pediatric chronic pain patients are a unique subset in contrast to other pediatric patients with chronic medical problems. Further studies might ask whether other groups of patients experience similar incongruity in their communication with their physicians. Perhaps the subset of children who have visited multiple physicians for chronic pain are a unique group for whom strategies that have been successful for other children may not be as effective. Comparative studies may provide some context for the physician’s perceived failure to address the chronic pain, patient’s concerns, or the child’s frustration that doctors only tried to treat bodily pain and ignored the social and psychological contexts.

In many chronic pain conditions, there is no simple answer to pinpoint the specific pathology, as one would do for an ulcer as a cause of abdominal pain. Whatever the inciting cause, the continuation and expansion of pain is related to complex, intertwining systems that involve neural pathways, neurotransmitters, thoughts, emotions, and other factors that are not captured in a biomedical “diagnosis.” In such a situation, sharp conceptual distinctions—physical or psychological causes or the reliability of the objective tools of biomedicine versus the subjective accounts of children—may prove inappropriate and unhelpful. The doctor-patient relationship must allow for both orientations and utilize a language that includes both direction and expression. Doctors should be willing to speak with children about the limits of diagnosis while acknowledging the reality of the pain and to introduce the idea of the biopsychosocial understanding of pain, namely, that children’s emotions, thoughts, neurology, and other biological factors interact to produce the experience of pain and suffering. Children’s activities in school and other social settings also influence the experience of pain. How these different aspects of pain are recognized and dealt with may determine the pathway to better functioning and reduction of suffering. Parents, of course, are an important influencing factor for children, and the complex interplay among children, parents, and doctors requires further study and is a component of our larger project.

The doctor who regards chronic pain solely or primarily as a condition to be eliminated through correct diagnosis and treatment will miss the point that pain always occurs in the context of lived experience in a social world. Oral testimony can uncover the social world of children in pain. Personal narrative can help the child, caretaker, and doctors make decisions that reflect the values and needs of the child, addressing the often submerged but vital questions for children concerning identity and self-definition: who am I and who do I want to be?

The only way that children know how to speak about their illness is by describing the experience of pain. This is the subject that they wish their doctors could understand and address:

PATIENT: Well, actually, I felt like they wanted to help me. I don’t think they really turned off to the idea of, like, getting me through what I’m going through, but I don’t think they fully understood what it was. I felt like sometimes they’d just go, oh, you know I went through the same thing, or like, oh, I have patients who have similar problems, but I never felt like that was true. You know what I mean? I never felt like they really fully understood

to the point where they—they'd always relate me to other patients, and I'd feel like I didn't have the same problem that they had dealt with.

Q: Did you feel like if they could have understood, they might have been able to help you more?

PATIENT: Yeah, I mean, it's such a hard thing to understand because I didn't really understand it myself. I mean, I didn't blame them at all. I didn't have any hard feelings towards them for not understanding but like I wish there was an easier way to express it or like there was more I could tell them. I mean, they could definitely feel the muscles tense and they could—it was really—like it wasn't hard to communicate what was going on was like the pain. But they'd give me suggestions of what to do, or they'd tell me like what to take or something, and it just didn't seem like a good idea.

The paradox of pain is that although it is a universal phenomenon it is experienced as personal and unique. Placing the subjectivity of experience at the center of its enterprise, oral testimony can be an essential source of knowledge about the inner life of chronic pain patients. The oral testimony responses of pediatric chronic pain patients show that children believe physicians are unable or unwilling to recognize the experiential dimensions of pain. By allowing patients to reflect upon and analyze their experiences, oral testimony gives us access and insight into the immediate, raw human story of children who live in the private world of pain.

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