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Learning from Stories: Narrative Interviewing in Cross-cultural Research

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Abstract

This paper argues for the importance of eliciting stories when trying to understand the point of view and personal experience of one's informants. It also outlines one approach to eliciting and analyzing narrative data as part of a complex and multi-faceted ethnographic study. The paper draws upon ethnographic research among African-American families who have children with serious illnesses or disabilities. However, it is not a report of research findings *per se*. Rather, it is primarily a conceptual paper that addresses narrative as a research method. Features that distinguish a story from other sorts of discourse are sketched and current discussions in the occupational therapy and social science literature concerning the importance of narrative are examined. The heart of the paper focuses on a single narrative interview and examines what we learn about the client and family caregiver perspective through stories.

Keywords

narrative analyses; ethnography; African-American; health care; phenomenology of illness and disability

Introduction

What can stories teach us about the experiences and beliefs of others? Why might a researcher want to elicit and analyze stories? Is there a difference between the ordinary stories we hear as part of everyday life and those we listen to as part of a research interview? This paper considers such questions, with particular attention to the power of narrative interviewing in conducting research with people from a variety of cultural, racial, ethnic and class backgrounds. While discussing narrative as a general research strategy, we also draw upon our own current research among African-American families who have children with an illness or disability, and the healthcare professionals who serve them.

This paper is not intended as a summary of research findings, nor is it a review article; rather, it presents an argument for the importance of eliciting stories when trying to understand the point of view of and personal experience of one's informants. It also outlines one approach to a complex and multi-faceted ethnographic study in which narrative interviews are a key research tool. Because this is largely a conceptual paper that addresses narrative as a research method, it is not ordered in the traditional categories of the research report. However, the paper does draw upon previously unpublished research data taken from

the authors' current research in order to concretely illustrate some general points about narrative interviews.

The general outline of the paper is as follows. First, we review current discussions concerning the importance of narrative for exploring personal experience, particularly as related to the issues of illness and disability. Secondly, we address a definitional problem. "Narrative" (or "story") is a term used widely, and used in many different ways. We briefly sketch some features that distinguish a story from other types of discourse. In the following section, we turn to our current research and discuss the narrative interview as a data collection method within an ethnographic study. Finally, we explore some stories told by participants in our research in order to ask what we learn about the client and family caregiver perspective through these stories. We also look at the struggle to elicit a rich story from one's research informant.

What can Stories Tell us? Stories in a World of Illness and Disability

Some basic understanding of a client's perspective is generally required in occupational therapy in order to devise appropriate treatment. When therapist and client come from a similar cultural background or share similar values, beliefs and experiences, such understanding may be readily established. However, when there are substantial differences in background and belief, misunderstandings are likely to abound and the effectiveness of treatment may be compromised. Narrative can play a potent role in helping to illuminate the world of the client—an especially important task when there are large differences between the cultural backgrounds of professionals and clients.

Very often, personal and cultural meanings and experiences are organized in story form by the participants themselves [1–8]. Many phenomenologically oriented medical ethnographers now believe that verbal reports in the form of narratives are the best way to discover a person's lived experience of particular events. While there is never any direct access to past experience, stories appear to be our best means of asking a person to "re-live" moments of their past, re-entering the rich emotional landscape of powerful experiences by telling stories about them. This re-entry is much more likely to provide "thick descriptions" [9] of the meaning of, say, having a child with a serious disability, or having a difficult (or wonderful) encounter with a healthcare provider. These rich narrative depictions are much more useful than abstract generalizations or belief statements in helping us to understand the complex and often quite tacit meanings (including dilemmas, hopes, anxieties and the like) that surround the treatment of children with special needs.

Commentators have noted the power of narrative in illuminating the world of illness and disability, particularly as experiences of illness or disability influence a person's sense of self. An interest in stories has grown remarkably over the past decade among researchers in the social sciences and the health professions; it is reasonable to claim, as Jerome Bruner does [10,11] that there has been a "narrative turn" in the social sciences. One key argument made by a number of scholars is that narrative is particularly suited to reveal the phenomenological aspects of illness or disability [5,6,12–17]. The surge of autobiographical writing by those with illnesses or disabilities attests to the power of stories in exposing how bodily suffering or stigma can shape a life. Notably, such storytelling illuminates meanings associated with disability or illness which are invisible when the body is treated in medical terms, through the language of disease and dysfunction. Stories, especially personal stories, often provide an "inside perspective," on what it is like for the person who experiences bodily suffering. As Kirsh [18] argues: "Narrative recreates experience through the eyes of the experienced, and brings with it the richness of personal and social history." Stories may offer a prime avenue for healing itself where healing is defined, in part, by a recovery of

self. Serious illness or disability may wound the person—robbing the individual of their sense of self—as much as it harms or impairs a body. “Seriously ill people are wounded, not just in body but in voice,” medical sociologist Arthur Frank writes, remembering his own struggles with a heart attack and cancer, “They need to become storytellers in order to recover the voices that illness and its treatment often take away” [19].

Narratives have been connected to an investigation of occupation, as theorists within occupational therapy have explored the link between making occupational choices and personal life stories [12,13,20–26]. Clark has made a strong argument that the deepest path toward an understanding of a person's “occupational being” is through an understanding of lives as storytelling and storymaking enterprises. Others in the field are also examining these ideas within their own work. Several other scholars have been intrigued with the possibilities of narratives in the form of life stories as an important element of occupational therapy practice itself [24,28,29].

Stories can also illuminate the experience of the healthcare professional [1,4,5,27,30–32]. Occupational therapists have turned to narrative to explore such matters as “the phenomenology of occupation as it was lived by the staff members” in day care centers for persons with dementia [33].

In studies of professionals, narrative is sometimes used to explore the reasoning of the practitioner. Narrative has played a central role in discussions of practical reasoning generally, and more specifically of clinical reasoning in occupational therapy. Here, narrative is examined as a way of thinking, a mode of cognition, and not only as a kind of discourse [10,17,32,34–37]. Occupational therapy researchers have investigated the relationship between telling stories and reflecting on practice [38,39].

There is more than one way to elicit and analyze a story. In fact, studies of narratives currently draw upon a range of analytic frameworks. Several research traditions have focused on narratives as a prime source of data within ethnographies of healthcare: (a) socio-linguistic and interactionist traditions that emphasize the actual communication patterns characterizing provider/client interactions or interactions between the person interviewed and the interviewer [40,41]; (b) cognitive traditions that examine differences in explanatory models [14], that is, differences in etiological explanation of a clinical condition between practitioners and clients and how this exacerbates misunderstandings [42,43]; (c) interpretive and phenomenological traditions that emphasize differences between a condition understood biomedically as a diagnostic category (e.g. a “CP child”) and as a personal illness experience for clients and caregivers [8,14,32,44–46].

What is a Story?

Sometimes stories that are analyzed by researchers are part of naturally occurring discourse, that is, they emerge in the everyday course of life and are recorded by researchers as they occur. More often, the stories that scholars analyze are elicited through interviews. But how does the researcher know when he or she has gotten a story? Is any sort of talk a story? What distinguishes a story from other kinds of discourse? On the one hand, stories are so common, so pervasive in our everyday life that it almost seems foolish to ask such questions. After all, don't we all know when we are hearing or telling a story? But of course, as in other common cultural matters, once one tries to devise a more formal definition, all sorts of difficulties arise. The very popularity of narrative across a wide range of disciplines has exacerbated the difficulty of pinning down a clear definition because narrative currently has such a broad reach. If identity itself is defined in narrative terms, as it often is [47–49] is there anything about human life which is not narrative?

In our research, and in this paper, we offer the following description. Narratives are event-centered and historically particular, located in a particular time and place. Stories concern action, more specifically human action, and particularly social interaction. Stories have plots. They have a beginning, middle and end, so that while they unfold in time, the order is more than mere sequence but reveal a “sense of the whole” [50,51]. Stories show how human actors do things in the world, how their actions shape events and instigate responses in other actors, changing the world (and often the actors themselves) in some way. Stories also reveal the way events and other actors act upon someone, shaping her possibilities, the way she views herself and her world. Whether hinted at or baldly stated, stories explore the complex motives that drive individuals to act in some ways rather than others and they also reveal the constraints of environment, of body, of social contexts that delimit a person's possibilities for action.

Not everything a person says in an interview is a story, even if someone is talking about their personal experience or their own history. It is common for people to talk in general and schematic terms about themselves and their lives. They might say, for instance, “Generally I spend most of my time in my garden” or “I am a very private person.” These may be informative statements. They may become part of stories. But they are not yet couched in narrative terms. Often stories about particular events are very revealing and it is not surprising that in interviews, respondents may prefer to offer general descriptions of states of affairs rather than talk in specifics about life events. One drawback of the general description is that often the listener does not really know the meaning or concrete relevance of such broad statements. What “private” means to the speaker may be quite different than its meaning to the listener. Stories of particular events, times when a person revealed their “private” personality, for example, can be extremely valuable in illuminating what kinds of experiences and actions the speaker refers to when she describes herself as private.

Here is an example of the difference between general statements and stories. A mother remarks, “My child is a wonderful artist, even if he has some learning disabilities. Even the OT says so.” This is not a story. While it tells us something, we can't be sure what constitutes “wonderful artist” to this mother, or even why being a wonderful artist matters so much. The gap between speaker's intended meaning and our understanding will be all the wider if we come from quite different cultural worlds. But a story about a particular time when her child revealed his artistic skills would give us much better understanding of these matters. It is often possible to shift someone into full storytelling mode simply by asking for an example. In the somewhat fictionalized example, the parent replies: “Just the other day, I was sitting down to watch TV and I noticed little Jamal had found some paper and some crayons and there he was, even with his favorite cartoon show on TV, not paying the least attention, but drawing the most beautiful pink and orange dinosaur! And normally he can't sit still for 5 minutes, but he just drew and colored for the longest time. One of his big brothers came running out of the other room, poking at him, but he didn't care. Didn't pay any attention to his brothers or the TV or anything. I had to drag him away from his coloring to come to dinner. And he is only 3 years old. I said to him, ‘Jamal,’ maybe you are going to be the next Picasso!’ And I could see he was real proud of himself and his pink dinosaur. Told me he was going to show Sally (his occupational therapist). You know, she's always getting him to draw in therapy.” In this tiny tale, it is easy to see the difference between a general statement about someone and a story that locates that someone (Jamal, in this case) in a particular time and place. A story does not need to have a complex plot, but it does need to have a beginning, middle and end, a space of time in which the story's protagonists carry out some actions.

Most stories, to be interesting, also have troubles and surprises. This tale, which isn't particularly enthralling, still does have a hint of surprise and trouble—Jamal is undeterred

either by the television or his pesky brothers from his drawing activity. This potential trouble, which Jamal overcomes (evidently by just ignoring everything) adds credence to the moral of the story, that Jamal is possibly a budding Picasso, or at least artistically talented. And more diffusely, it communicates that even if Jamal has some disabilities, he also evinces some extraordinary gifts, and at only 3 years old. The story also suggests that this is a parent who is able to see a child's abilities and not just his handicaps. This net of implied morals emanate from even the smallest story about a routine and mundane event. Notice, too, how such a brief story can help give us a glimpse into the daily life of Jamal and his parent which a simple statement "my child is a wonderful artist" does not do. This little story does not go very deep and perhaps it does not tell us nearly as much as we need to know about this parent and her experiences of her child as artist. But it draws us, if only for a moment, into a bit of her world and helps us glimpse what life is like when her child shows his artistic side. Notably, this story need not be completely factually accurate to reveal a great deal about this mother's experience and perceptions of her child the artist.

This example just given is loosely based on a child who is part of a study we are currently conducting. In the remainder of this paper, we discuss this study, examining narrative interviews as part of the research process and why they have been so critical as part of our research.

Narrative and the Exploration of Meaning in an Ethnographic Research Study

The examples we offer in this paper come from our current research in Los Angeles, as do our descriptions of the place of narrative interviewing in our ethnographic research. However, we have carried out some smaller ethnographic studies along the same general lines in Chicago as well. For the past 8 years, we have been conducting research among African-American families in both Chicago and Los Angeles who have children with serious illnesses or significant disabilities. Most of these families are low income, all live in the central city or nearby urban centers. Both Los Angeles and Chicago are similar in presenting challenges to healthcare professionals who provide services to a multiplicity of ethnic groups. The challenges inherent in serving both specific ethnic groups and multicultural populations are particularly evident in these urban settings. Ethnic populations display a range of beliefs and attitudes about the roles of family caregivers and the meaning of disability, which affect the therapist/client/family caregiver relation. Many healthcare professionals talk about the fact that they are not prepared or don't feel knowledgeable enough about the wide variety of cultural groups and practices they find in these urban settings. However, they must deal with cultural difference on a daily basis. And of course families too, face a similar problem when they bring their children for care and encounter healthcare professionals who come from very different cultural backgrounds from their own. These actors are faced with what may be a delicate set of transactions across cultural boundaries. For the good of the child, they are compelled to try to find ways to communicate with and understand one another. It is this particular task which we seek to understand in our research.

Currently, we are in the midst of our third and final year of an ethnographic study with 30 African-American children with special needs, their families and the healthcare and school providers who serve them. We are specifically interested in how the problems of these children are variously understood of "framed" by family members and healthcare practitioners, including occupational therapists, physical therapists, speech therapists, nurses, social workers, physicians, special education teachers and healthcare aides. We are particularly concerned with the influence of different frames on the intervention process. We have examined the processes undertaken by family members and practitioners to negotiate

or impose alternative views and we have explored the impact of these multiple perspectives on the effectiveness of interventions.

The research focus of this study concerns the task of communication between the family and the various interdisciplinary team members of the child's healthcare services network. In essence, effective communication requires crossing cultural boundaries created by the multiple cultural worlds that intersect in clinical interactions. Both family members and practitioners live and operate in a multiplicity of cultural domains shaped by their profession, economic class, ethnicity, and community affiliation. When practitioners and family members interact, their values, assumptions and perceptions about the interaction are shaped by their membership in these cultures.

The difficulties and complexities attendant upon “partnering up” are very often heightened when professionals and their clients come from different ethnic, racial or social class backgrounds. Miscommunication has been well documented in the case of minority clients receiving healthcare services from physicians [42,52,53], though it has been less well investigated with other healthcare professionals. There are some compelling reasons to suppose that in the area of rehabilitation, successful outcomes will be particularly dependent upon success at partnerships and at communication and understanding across cultural boundaries. Comparative anthropological studies of cultural attitudes toward disability and chronic illness note that different cultures and ethnic groups are likely to see disability differently and have different strategies for dealing with it. The same disability does not necessarily carry the same meaning cross-culturally [14,42,54].

Cultural, as well as individual, differences exist between patients' families and providers. DiMatteo [55] argues that medical care, including the most technical of services, consists of “reciprocal social exchanges” and physicians as well as patients must be aware of what they each hold “to be true about the therapeutic relationship (i.e. their beliefs, viewpoints, philosophies, and expectations)”. Both the patient and the provider operate from different types of cultural knowledge. In other words, what is accepted as everyday knowledge in one culture may be unknown to another. This incongruity can be important in early intervention care because of different assumptions about the structure of the family, family identity, parenting roles, and the meaning of disability.

How can the study of participant's stories aid in this investigation of multiple cultural worlds? How are stories elicited? What do they reveal about the lives of participants? How does the study of participants' narratives fit within an ethnographic design?

Narrative Data as Part of a Multi-Method Ethnographic Study

In our research investigation of African-American families, their children with special needs, and the healthcare providers who serve them, narrative interviews represent only one among a number of other data collection strategies. We have drawn upon a variety of methods which include extensive direct observation and videotaping of clinical interactions, interdisciplinary team meetings, intervention planning with families, disciplinary discussions, informal settings (e.g. waiting room, lunch room, staff lounge), administrative meetings, and in-service training sessions. We have also done observations and videotaping of family life at home. Because we are interested in the complexities of clinical encounters as cross-cultural events, and we recognize that the meaning of these events depends upon what participants bring from other powerful cultural contexts to the clinical situation, it has been important to collect observation and interview data from a number of different actors, ranging from various healthcare professionals to family members.

While it is beyond the scope of this paper to discuss how these various data collection strategies work together, it is important to recognize that narrative interviewing may often happen within the context of a multi-method ethnographic design. Indeed, there are strong reasons to try to combine observation with interviews in order to enhance the validity of one's findings. In our study, as in most ethnographic research, data comes from two sources: participant observation and open-ended interviews with research participants. Narrative interviews are sometimes considered one particular type of open-ended interviews, but because humans are such natural storytellers in many cultures, it is not uncommon for ethnographers to hear many stories even if they are not specifically interested in narratives.

Our research begins not with interviews but with observation as we begin to try to become familiar with key contexts that we are trying to understand. Since a primary question for this research is the clinical encounter, initial observations began in two clinical sites, which became the key institutional contexts for this study. Naturalistic observation involves discreet observation and note-taking, but no interference with usual clinic, school or home life. As is traditional in ethnographic research, observation data is recorded in field notes. In our study, observations occur within a wide variety of spaces within the clinic environment, from formal team meetings and treatment sessions to informal, but often extremely important, settings where professional colleagues interact (e.g. the lunch room or staff lounge), or where professionals interact more informally with clients and families (e.g. the waiting room). Past research experience reveals that informal settings within the hospital environment, such as waiting rooms and lunch rooms, can often be places where a great deal of "problem setting" and negotiation occurs. As part of this process of learning the clinic culture, we review documents. Formal written records reveal the "espoused" assumptions and values of an organizational culture, including formal organizational rules and visions for the organizational future.

We conduct a number of different types of narrative interviews. One type, which we will discuss here, is the "illness narrative" [1,8,14,17,44]. In our research, illness narratives are elicited from family members concerning their experiences caring for their child. Although, of course, family members may not be suffering from any illness or have a disability, an entire family experiences the illness of a child when they are directly involved in caring for that child and when that child plays an integral role in family life. Thus, speaking broadly, we can talk about a family member's "illness narrative" [46]. We also elicit and analyze "treatment stories," that is, narratives of treatment offered by both healthcare providers and family members in interviews. As part of the interviewing process, participants are generally asked to tell stories about particular critical incidents in their interactions with the child and his or her illness.

Through all these ways of collecting narrative data, we are able to investigate the clinical encounter as a short story nested within much broader historical contexts. From the professional side, these larger narrative contexts will include the practitioner's history of work with this particular client, within this particular institution, and within a professional career. From the family caregiver's side, larger narrative contexts include the illness story from birth to present, and the family history of which the story of parenting this particular child is just one piece. Family history not only includes the family configuration current at the time of the child but also a history of past generations of family life. Out of this multi-generational investigation, we explore patterns of care giving that have evolved within a family culture and how these provide both resources and limitations in the immediate caregiving situation that involves this child with special needs. Interviews that reveal these multiple layers of narrative context allow us to examine the problem of disparities of perception among the key actors (including the child) interested in facilitating the development of the child.

We now turn to a concrete example.

An Illness Story: Two Fateful Trips to City Hospital

The remainder of this paper describes the process of eliciting narratives by focusing on just one of these several types of narrative data—the sort of storytelling that emerges through interviewing. We examine an illness narrative told by the primary caregiver, in this case a mother, Barbara who is in her early forties and finds herself caring for her critically ill 5-year-old child, Rhonda. Barbara and Cheryl met in the fall of 1997 about a month after Rhonda was originally diagnosed when Rhonda was 3 years old. Barbara is a warm person, very willing to talk freely about her feelings, though she repeatedly notes that there are things she tells us she won't repeat to her family or friends. We researchers “keep things to ourselves,” as she says, and this is important to her. Also, since our task is listening to what she has to say rather than intervening, she has the refreshing experience of being able to talk about her own experience or voice her opinions without getting lots of advice or admonitions.

The story recounted below is at once highly personal and individual (about a particular mother and ill child at a particular point in time) but it also offers a vivid example of one of the most distressing aspects of contemporary healthcare in urban America, especially among poor minorities. This is the difficulty of receiving timely healthcare treatment. While there are numerous statistical studies that document this difficulty, there is little known about how minorities themselves experience and address this problem. What is it like for them? How does delayed diagnosis affect the experiences of the patient and of family members who deem themselves responsible for the welfare of the patient? What kinds of actions do family members take to try to receive healthcare? What happens to them when they do?

When we began this research, the difficulty of getting an accurate diagnosis was not high on our list of topics to be explored. We were much more interested in treatment, particularly at the hands of rehabilitation therapies such as occupational therapy. However, because we were following an ethnographic design and asking for the “illness story” of the child, as told from the parent's perspective, we discovered again and again that an essential element of this story was the drama around receiving a diagnosis. We were “forced” by the stories themselves to shift our attention, recognizing that from the family perspective, the struggle to receive healthcare was a fundamental part of the illness story and we could not afford to ignore it.

During the first interview with Barbara, she told a harrowing story of how she struggled time and time again to get health professionals to find out what was wrong with her little girl. The following extensive excerpt of this first interview gives a powerful picture of this struggle. Since it includes the interviewer's (Cheryl's) questions, it also illustrates the kind of questioning process often required to prompt someone to move from broad descriptions of situations to vivid and fine-grained stories of particular events.

Three people are present in this interview, which takes place in a hospital waiting room. Barbara, the mother, Cheryl, the interviewer, and Rhonda, the ill child. Rhonda, who is just 3 years old at the time, becomes impatient in the way that children do and interrupts, forcing the adults to pay some attention. Barbara is adept at shifting between responding to Rhonda and picking up her narrative train. Cheryl lacks Barbara's easy facility, but tries valiantly to keep Rhonda entertained while listening to Barbara's story. She also tries to keep the tape recorder out of Rhonda's hands who gets curious about how it works. Cheryl has supplied Rhonda with some colored pens and paper since Rhonda loves to draw.

At the stage of the interview excerpted below, Barbara has been remembering the period of several months in which Rhonda has often been violently sick to her stomach, but no doctor has discovered anything the matter. She then remarks:

So on Labor Day (pause) Labor Day, her Dad had her ... and he was keeping her till the next morning. So the next morning, at 5 o'clock, he called and said, "Oh she's really vomiting bad." And I said, "Bring her here so I can take her," I said, "I'm taking her to City Hospital." So I said, "Bring her here."

The very way that Barbara has phrased things signals Cheryl that a significant moment is about to be described. A key marker of a story is the location of an event in a specific time. Barbara begins this part of their conversation with specific temporal indicators. Not only Labor Day (a 24-h time period) but even "5 o'clock in the morning." Here is the verbal equivalent of a zoom lens, which moves from a hazy distance to an increasingly sharp focus on one particular moment in time. Barbara is setting the stage and we know that something important is about to happen. A second marker that a significant story is about to unfold is Barbara's narrative strategy of recalling dialogue. She shifts into a "he said, she said" mode in which she not only simulates the remembered phone conversation, supplying actual conversation, but she even shifts her voice to imitate the various characters, namely herself and her estranged husband.

While, upon reading the transcript, it is clear that Barbara is heading in an important direction, at the time Cheryl seems a bit oblivious to these clues and asks a series of distracting questions, which Barbara politely answers.

C: Had you been to City Hospital yet so far?

B: No. "Cause I couldn't ...

C: It's a long trip.

B: And plus the job. I figured the pediatrician that I was taking her to, that she's had ever since she was born—that, you know, they would handle it, and plus, I was at the kind of job that I couldn't, like, take off, you know, or, you know, I was always stressed that if I take off, you know, that I would lose my job, you know?

C: Yeah.

B: And, especially since I had got separated. You know, I really couldn't afford to take no time, you know.

C: Yeah.

But then, tenacious storyteller that she is, when Barbara sees an opening she returns to her story as though she had never been interrupted.

B: So, I was taking her, you know, to a lot of the emergencies and to, you know, X Hospital and Y Hospital, and I was taking her there, but then I started just saying, forget it. [Barbara means here that she finds she is not getting any helpful treatment for Rhonda and gives up on the idea of continually taking her to the doctor's.] I started taking her to my ex-husband's place. And so, he didn't bring her home that morning when he called me at 5 o'clock. He brought her home, like, later in the afternoon. But by then, she stopped vomiting, okay? But later on that evening, it started back up. She just, like when she was drinking something, it would, like, just shoot back out across the room. Just like how the Exorcist ...

C: Yeah, yeah.

B: You know? And I was, like, really getting, um, crazy, so I had brought her down ... I called Z Hospital, and I told them that my daughter's like, vomiting and having headaches, you know, and um, they said, well um, "Bring her." You know, and then so I brought her to the emergency there. And then, um, I had a little confrontation with the lady in there, okay?

In this passage Barbara begins the shift from general description of her life to specific, vivid storytelling. She begins with an overview of her situation during this time prior to Rhonda's diagnosis in which she speaks about her difficulties in getting time off work and her continual trips to various clinics in the area. But then she switches to a specific highly dramatic incident, which she locates at a specific time, "that morning." Though her account is a bit confusing in detail, it is clear that something much more frightening is going on with Rhonda than has happened before. Barbara uses a graphic image, vomiting like "the Exorcist" to get her message across of what this experience was like for her.

At this point, Cheryl has caught on that this is a pivotal episode in Barbara's illness story. She suspects that Barbara's phrase "little confrontation" is the tip of an iceberg and that much could be learned about Barbara's perspective on what it is like to deal with healthcare professionals if she can get Barbara to tell the story of this "little confrontation." Cheryl also hears in Barbara's voice that, whatever else, this confrontation is not little, is in fact momentous. While Barbara has already shifted from general description to narrative, her short story indicates that she has a much longer one to tell, a story which will reveal something about her experience of trying to get healthcare for her child. While the following story that Barbara tells about her difficulties are highly specific, her vivid specificity provides a powerful example of a key theme in our research, the struggle of many minority parents to get adequate access to proper healthcare and their fears that their race and economic class work against them. Such difficulties are already well documented in the literature, but Barbara's story does more than illustrate this general problem. She powerfully portrays what the experience feels like from the inside, and draws the listener into the tale. It is difficult adequately to convey the power of her storytelling in a written transcript, but suffice it to say that the interviewer was nearly in tears as she listened to it.

Cheryl moves in to facilitate the storytelling, drawing Barbara out and slowing her down by asking her to describe, in graphic detail, what happened in that confrontation. As Barbara answers, Cheryl requests even more specificity. Twice she asks that Barbara remember and repeat the actual words of participants. Barbara responds by telling the story in greater and greater detail and as she shifts to this increasingly vivid portrayal of the dramatic scene, Cheryl only needs to sit back and listen, to murmur and show, through her body, that she is intently following Barbara's story.

C: Tell me about this. Just describe that. What happened?

B: Yeah. That evening, when I brought her um ... the doctor down there in the emergency, she um, came and checked her, and I was telling her, she's really ... she's constantly vomiting and having headaches really bad. And she did her little checking, and she said, "Well, I don't see anything." And we did her urine and, "I don't see anything." I said, "But I'm not leaving here unless you guys tell me to do something because ..." and then she started, like, getting a little smart on me.

C: Yeah, like what did she say? Just go ... just go through this.

B: Okay. She was, like, saying, well, if you don't think that I'm doing my job, then you could just take her to the, um ... I'm gonna make you an appointment and you can take her to the day hospital. I said, "Oh, it's not that I don't think you're doing your job; I just want my daughter to get help." You know, as you understand, I've

been taking her everywhere and she still be doing the same thing constantly, over and over. And so then, she got a little upset, so she left ...

C: What did she say?

B: And she went across the hall and ... where her little office was ... when all that time, the door was open, you know, all the time she was seeing patients. But when she left there from talking to me, she went over there and she closed her door, and I guess she was telling the social worker ... because the social worker came down and came in there and talked to me and was asking me, "What's going on? Is there something wrong?" I said, "Yes, there's something wrong." She said, "Well, the doctor feels that you don't think she's doing her job." I said, "So, but why does she have to call the social worker on me?" You know? And then I started feeling like they was, um ... I felt like she thought that I was, like, kind of crazy or did something to my daughter myself. That's the kind of feeling I had got. I felt very uncomfortable. I said, "Do you guys call the social worker on all people?" You know? And she ... and I was letting the social worker explain. "No, it's not on all people. It's just when the parents feel that your not happy with your doctor, and the doctor will call." You know, but then, she kinda calmed me down. You know, I wasn't arguing or I wasn't saying any, you know, bad ... anything ... I just wanted my baby to get help, you know? I didn't want to take her home again and be like she was. You know, she'd done been through it too much.

C: Yeah.

Barbara's poignant story recounts how her struggle to get care for her child triggers a "little confrontation." In her story she tells an emergency room doctor "I'm not leaving here unless you guys tell me to do something." She subsequently points out in an aside to me, explaining her strong words, "You know, as you understand, I've been taking her everywhere and she [Rhonda] still be doing the same thing constantly, over and over." Her contentious statement to the doctor results in an angry retort from the doctor who starts "getting smart on" her, saying "well, if you don't think that I'm doing my job, then you could take her to the...day hospital." The doctor then disappears into the safety of her office and sends out a social worker. Though Barbara does not mention this in her story, an important piece of shared background knowledge is that in hospitals, as is typical in a number of institutional situations where trouble appears to be brewing among low-income minorities (and perhaps especially African-Americans) social workers function as quasi-police who can be called in to deal with difficult situations.

Barbara's account is very different from the emergency room doctor's, whose view is revealed in fleeting medical chart notes. The doctor writes in the chart that there is a "vague history of complaint" and then adds that there is a "social problem, refer to social work" and offers "Diagnosis: vomiting, psychosocial concerns, parent-child conflict." The presumption that conflict lies with the parent, or the parent and her child, rather than representing a legitimate concern for a child's safety and health is a powerful theme in the episode Barbara recounts. However, without Barbara's story, it would be easy to miss her deep concern and terrible fear, to overlook that her confrontation is spurred on by a several month frightening history of severe illness in Rhonda, any number of days missed at work, calls from the school that Rhonda is sick again, vomiting so severe that it reminds Barbara of the possessed child in a famous American horror movie, "The Exorcist."

This "little confrontation" is not the only thing that makes this particular instance so memorable for Barbara. It forms the critical initial episode in the struggle to get crucial medical attention for Rhonda. This confrontation, is repeated and amplified just 1 week later, in September, when Rhonda is again severely ill and Barbara picks her up from school

and rushes her back to City Hospital. Again she has to fight with nurses, doctors and other healthcare workers to get her child seen. Barbara tells the story of this fateful day. She talks to person after person, going from one department in the hospital to another, telling them “that nobody wants to see my baby ... I said, ‘Nobody wants to see my baby and she’s really sick, and I keep getting the run-around.’” She remembers that they tell her, “‘Well, Rhonda’s appointment is not until the 21st,’ you know, ‘of October, so you have to wait.’ Finally, she gets one “administrative lady” to listen to her and this woman locates Dr Romburg. “And so he was doing a little history on Rhonda...I said, “My baby keeps complaining of her headaches.””

Just then, the doctor has Rhonda walk. Barbara recalls her horror at what happens next. “But she started walking like she couldn’t walk by herself anymore, you know? And started walking, like, into the wall, you know, to the right. And I said, ‘Oh Lord! Something is really going on.’” The doctor then “hurried up and ran and got another doctor...and he told her to walk for him, so she did the same thing for him. So then they went and talked and they came back. They said to me, ‘It seems like it’s some form of a mass or something, pressing down on her head to give her headaches.’ So then I was sayin, ‘Oh Lord.’” As terrified as Barbara is, there is one phrase this doctor told her, one she repeated several times and in later interviews again, that deeply reassured her. While others had only paid attention to Rhonda’s stomach because of her violent vomiting, “Dr Romburg, he said, ‘We’re gonna start from her head and work our way down.’”

Again, note the contrast of Barbara’s wrenching story to the pristine note in the medical chart in which the doctor reports, “Physical examination: looks well but wobbly ... has me concerned about mass in head, will schedule CT.” No one would know what Barbara endured to get this essential CT scan, which led to Rhonda’s diagnosis of a brain tumor just 3 days later.

Barbara’s story, which emerged in this initial interview, and is partly recounted here, is one of many stories we have now heard from Barbara. It constitutes a narrative about certain fundamental episodes in Rhonda’s illness as these have become nested within a much larger and more complex history that has unfolded in the subsequent 2 years. Rhonda is now 5 years old, still very sick, still receiving treatment, but still alive. Barbara has retold this story more than once over the course of our own relationship with her. She now speaks more freely to us as white researchers about her fears of being seen as one of “those kind” of black women, by which she means the kind that make trouble, that “act ghetto” as another mother in our current study puts it. Some of the meanings of these early events have also changed for Barbara as she has had to learn how to deal with healthcare professionals since Rhonda’s initial diagnosis. Although Barbara’s story, told in that first interview, has gained complexity and depth over this 2-year period, it also stands by itself as a powerful illustration of the kind of story which patients and their family members often need to tell when they encounter the terrifying world of serious illness and the equally strange and frightening world of institutionalized healthcare. There is much to be learned about how to help patients and families face these situations by letting them tell their stories.

Conclusion

Stories are powerful. They can help us, as researchers or healthcare professionals, to understand those we seek to help in ways that nothing else quite does. They can also provide a place for those who may find themselves stripped of their voice in the face of a daunting healthcare system or a frightening disease. A rediscovery of voice is especially significant for those whose ethnic or racial background leaves them feeling particularly misunderstood,

voiceless or overwhelmed as they face not only serious illness or disability but a terrifying healthcare system as well.

For those with disabilities, storytelling may offer its own kind of healing. Though it may not cure, its absolute importance is reiterated with increasing force by contemporary writers who narrate their terrible travels in the world of illness and disability, who struggle against unimaginable physical difficulties to tell their stories. We conclude here with the words of Jen-Dominique Bauby, a man suddenly afflicted with “locked in syndrome” after a massive stroke. He tells of a life in which “paralyzed from head to toe,” he finds himself “imprisoned inside his own body, unable to speak or move” [56]. How is he able to tell us about this imprisonment in the months before his death? Through a wondrous, excruciating writing process in which blinking his left eyelid is his only means of communication. He is trapped in a “diving bell” he writes, though sometimes his “mind takes flight like a butterfly.” Where does he go? “There is so much to do ... you can visit the woman you love, slide down beside her and stroke her still sleeping face. You can build castles in Spain, steal the Golden Fleece, discover Atlantis, realize your childhood dreams and adult ambitions” [56]. What a difference between that outward body, what others see and “handle” and these dizzying travels when his mind takes flight. His outward self, as expressed through his paralyzed body, reveals nothing of the delicacy and grace of his mind. Its gracelessness is emphasized in the daily rituals of life in the hospital. “Two attendants seized me by the shoulders and feet, lifted me off the bed, and dumped me unceremoniously into the wheelchair” [56]. His descriptions give voice to this contrast and allow us into the drama of his inner world. Without his story, which paints an inner landscape as well as an outer one, we could never guess how it is for him, the depth and terrible beauty of that phenomenological terrain.

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