Welcome. You are listening to the UC Davis Center for Poverty Research Seminar Series. I'm the Center's Director, Ann Stevens. This series brings scholars and policy experts from around the country to discuss their work on poverty and poverty research. In March 2013, we hosted Cheryl Mattingly. Professor of anthropology and occupational science and therapy at the University of Southern California.

Her work examines stories in healthcare. How clients, families, and clinicians work together in the practice of rehabilitation and clinical reasoning in occupational therapy. Here is Mattingly presenting her seminar: Rambo Mom as a Moral Tragedy, an African-American mother's struggle for clinical care.
>> I know this is a very interdisciplinary group from what I understand.

It's a pleasure to talk to a group of people who evidently really care about poverty and are willing to meet together in some interdisciplinary way to think about it. I also understand from Megan that you often have very lively discussions here, and I'm really looking forward to that.

But I would, if you don't mind, I would like to actually to give my talk first, try to make sure I've, I've whacked it down I hope, sufficiently so that I give time for discussion. But I kind of like to go through the whole thing before we get into that and although the title is got Rambo Mom as the first person, I'm actually going to begin with a story, and I'm going to introduce another mother who I will call Andrina.

Rambo Mom will appear, but not quite yet. The first time I interviewed Andrina was in the main lobby of a large, urban hospital. A cavernous space, strangely dark, even formidable. Later I could see that the gloom had its comfort. A good place for quiet crying or for staring into nothing.

High ceilings, clusters of permanently fixed plastic chairs lined in, lined up in rows of three or four, or set together in L shapes. Chairs as neutral as could be in tones of beige and practical brown, placed neatly on the wall to wall gray carpet. Some leafy potted plants, plastic too, but the realistic kind, help divide the room into smaller waiting areas.

The lobby always felt empty, odd for a hospital full of children. At one end, almost unnoticeable, was the Receptionist desk. Though these are often busy hubs of clinical stasis, this one was far away, which gave the impression of a waiting room with nothing to wait for. Of course, I could have some of these details wrong.

This interview took place many years ago. The fall of 1997, and the hospital was redecorated two years later. I didn't mean to talk to Andrina in such an anonymous place, but where could I go? This was new research in a new city. Sometimes you can find a cozy enough corner even in a big hospital, but I didn't know my way around, and Andrina's very ill daughter was lying in a room three floors up, so she was not about to go far.

I'd only met her once, a week earlier, in her daughter's room on the East Wing. I was introduced by the friendly speech therapist, who thought Andrina might be willing to participate in the study my colleagues and I were doing. When I saw her that first time, she was sitting on a chair, holding her daughter's hand.

A little girl of four and a half, whose shaved head was barely visible above the white sheets of the bed. The small half room was jammed with people. People standing, sharing chairs, leaning against the radiator or a wall. The child's father, a grandmother, an older sister, an uncle, a cousin.

Before we entered, the speech therapist told me that the parents were separated and Andrina was the one to ask. After some quick introductions, I directed my attention to her. To my surprise, her daughter looked so frail and her mother held her hand so tightly. She smiled and agreed immediately.

Sure, sign me up, she said. I'd be glad to help. I left a few minutes later with the plan for our first interview. So there we sat, Andrina and I, in the twilight of that lobby. Diagonally faced in our plastic chairs, my paper quarter perched in between us.

Andrina was one of those I could see who wasn't in the mood for leisurely opening remarks, so I said, can you tell me the story of your daughter's illness up until now? Just begin at the beginning, wherever that might be for you. And then she started to talk.

She talked for an hour and half with very few questions from me, and there was no wasted words. One episode of that first long story offered me a beginning, too. The more I've considered it over the years, the more it has haunted me, or perhaps beckoned me. After nearly a year of struggling to find out what was wrong with her child, who was growing increasingly ill, Andrina finally got a diagnosis.

The relief at being taken seriously by clinicians was quickly replaced by the terror of what she found out. Her daughter had cancer, a brain tumor. As if that news weren't terrible enough, she was pulled aside by one physician who announced that the particular type of cancer her daughter had was the worst kind.

Here's how Andrina put it. I'll give you a lobby to look at. This one doctor, a lady doctor, she came to get me to explain what they were gonna do. And she came and she took my daughter and myself to this one room. And she really largely had me going crazy because she told me, she said oh I'm so sorry.

I said, so sorry, did you hear something else? And she said well you know, that's the worst one that a kid could have, it's the highest risk kind. And I said oh my god, I started saying oh I'm dreaming, I'm dreaming, I'm dreaming. It was like, this was like, it was like something on TV or something.

Her dream, a nightmare in fact, seeped through the whole of her life, and as she gradually discovered there was nothing to do but learn how to navigate in it, even learned to make it a new kind of home, a home where she struggled to hope. In this paper, I wanna look at this narrative shape of hope.

Hope that is not merely cherished or passively received, but actively cultivated and practiced. The research I'm drawing from today explores how a group of African American families, many of them poor, traverse clinical spaces when their children have serious, chronic or sometimes critical medical conditions. We have also, we the research group, have also considered these navigations from the perspective of clinicians.

Who, at times, find themselves confused and uncertain about how to provide care, or how to connect with families far removed from their own class and cultural background. Hoping is no personal, mere personal affair when it comes to health care in a multicultural urban clinic. It is a border activity.

One, one question that I want to consider here, is how is hope cultivated? And how is it thwarted in a border zone? So the lobby. It's become quite popular to talk about life on the borders. Not only in politics, but in the academy, across a whole range of disciplines.

The recognition that social worlds are poorest, that boundaries are fluid and contested, that objects and people are bound together or travel in all manner of unexpected ways, continues to inspire our imagination and provoke our attention. Here, I'm thinking about the clinical setting as a kind of borderland, using that metaphor.

And so some of the things I'm taking are actually from this book that Ming pointed out. Before I, okay no, you can't see that yet. Sorry. Back here. Cultural travelers like Andrina suddenly find themselves faced with trying to understand and navigate the foreign world of pediatric ontological care.

She has new languages to learn, languages of disease, of rehabilitation goals, of x-rays. New social spaces to traverse, radiology labs, oncology reception desks, physical therapy mats. New roles: the patient's mother, the home co-therapist, and new technical competencies to master: how to administer chemotherapy shots to her daughter at home.

How to do the OT artificial therapy treatment home program. How to become deferential to novice clinicians, even when she has acquired better mastery of some, of some of their technical skills. Better for example, at giving shots to her daughter than some of the nurses were. Most complex, she has the task of trying to create effective partnerships with a vast array of health care providers.

The lobbyism metaphorical image suggests more than a spatial borderland, however. It intimates an imaginative space marked by temporal uncertainty. One way can a lobby not only for a person, a place, an activity, some news, but for the future itself. Temporally space, lobbies are spaces of the not yet.

In this sense, they suggest a frontier characterized by anticipatory imagination. As I discovered in my earliest research in the clinical world, the imaginative plays a very central role in the cultivation of hope. That accompanies serious illness, and I'll say more about this shortly. But very briefly, unbelievably briefly, I'm going to just say, tell you and we can go back if you have questions, about the methods of this research, and a little bit about the parameters.

So you know I did research and I don't just make up stories. Or even if I just make them up, still there is research behind it. I shouldn't even joke about that. I'm an anthropologist. You need to take me seriously. There might be economists in the room. okay.

So this this the story that I told you, the research I'm going to talk about today started to talk about, is based on an urban ethnography, a longitudinal ethnography that began back in 1997 and went on until officially only ending in 2011. And it the interdisciplinary team, I haven't done this by myself, it's been a whole mixed team of clin, people with clinical backgrounds who have been trained as ethnographers and well as a group of anthropologists, linguistic, medical, psychological.

We followed a cohort of a actually a little over fifty African-American children with an array of chronic illnesses or disabilities. So it's not been a medical diagnosis driven study. We've been interested in the experience and the practice around chronicity. And so we get kids, and we get families, and we get the practitioners if they wanna sign up, who serve them.

So altogether, we've had almost 600 participants. So it's not so small, and hundreds of thousands of pages of data. All right, health disparities, I, well it's a little bit, can you read, see this? It's a little, anyway, this is not really a very interesting slide. But just to say I'm sure all of you are quite, or many of you if you're interested in health care at all, know something about health disparities research.

And I don't want to really talk about it in any detail. But just to point out that this research that we have conducted has very much been in the, in the tradition of health disparities research, although the methods of being ethnographic and even phenomenological are maybe not so usual.

So as you might very well know, in health disparities research, two interc, inter-related concepts are frequently cited around which research has been conducted. One concern's what sometimes have been called structural barriers. You know, big economic bureau, obstacles, bureaucracies, fragmentation of service, that kind of thing. And then a more intimate, but closely inter-related research focus on what are sometimes called interactional barriers, which are really much more about the communication issues between healthcare professionals and clients.

But I keep emphasizing inter-related, because of course these are all tangled up together. So our particular research has addressed some things that have been less studied in health disparities research or so we argued to our funders, and think it still holds true. Historically certainly, there's been far less research concerning children, which link children, disability, and health disparities together.

Also a lot of the research that has been working on the interactional issues, which are more the forte as you can probably already tell, of what I'm talking about. Have tended to focus on patient-physician relationships, without paying so much attention to the many, many other health professionals that are part of the health care experience and health care encounter for parents.

And that's quite important to the borderland, quality of that experience from the parents' perspective. Also, a lot of research has been focused on retrospective information versus our ethnographic approach, which has been based on a lot of observations, and even videotaping of clinical encounters. And finally, although there certainly are some longitudinal studies, there aren't so many that trace the impact of clinical encounters, and relationships over time, in a cross context.

Which is what our research has been designed to do. So, many methods. I will, you can ask me about them later. But the only thing to add, because they're in some ways traditional anthropological methods, is our micro-ethnographic focus on videotaping. Which is not always part of ethnography. Many settings including not only institutional settings but if, since we're following kids and kids evidently go a lot of different places, I've been to Chuck E.

Cheese and the other spots. So homes, neighborhood spaces have all become part of the study. And we've gotten funding from Maternal and Child Health, and then a series of NIH grants over the years. The key research focus of the grant as a whole has been of the study as a whole has been trying to look at how communities of care, that can cross bound the borders between the clinical world and the home world.

How these are cultivated, how these partnerships are cultivated. Where they run into trouble, between clinicians and family caregivers, often in very daunting circumstances. So we've been interested in obstacles, but we've also been interested in, about when things work and why they work. How does that happen? so, and we've been very interested in focusing on African-American families in the place of race and class and other social markers in this partnering up process.

And have wondered how examining a part, this partnering up process and it's vagueries and how it works between family caregivers and clinicians. How, what this suggests about the production and potential amelioration of heath disparities. More, so, remember I've said chronicity, so chronicity means you know, there's not, either there's no cure, or there's unlike, very unlikely cure.

That's the kind of group of people we've been following. And it also means that a lot of the caregiving, and we know this also in looking at poverty, a lot of it happens with family caregivers, unpaid or poorly paid and at home. So then, finally, from our perspective, what can a narrative framework offer in addressing these kinds of questions?

So I'll just point authoritatively to some doctors to say I'm not alone in being interested in narrative. There is, some of you might know about this, a narrative medicine movement, which has been very much physician driven in the last 10 or 15 years, in which medical schools have increasingly taught or tried to teach skills in to their students in learning how to tell and listen to stories.

Making one kind of argument, here's a co-authored paper with Rita Sharon, who's at Columbia, who's a big narrative medicine person in the U.S. and who has argued that this is already happening in clinical practice. This is kind of very important to clinical practice, this telling and hearing stories.

And the two, two key people in the U.K where this has also been a big movement have Trish Greenhalgh and Brian Hurwitz, here's one of their quotes. Like why pay attention to narrative, you clinicians? Here's what they say. Even the most pompous professors have been known to warn their students.

Listen to the patient. He or she is telling you the diagnosis. More sophisticated view holds that when doctors take a medical history, they are inevitably, they inevitably act as ethnographers, historians, and biographers who require to understand aspect of personhood, personality, social and psychological functioning, as well as biological and physical.

Okay so, narr, these narrative, this narrative approach, and these narrative methods, which have been an attempt to sort of humanize medicine, have also been part of social justice efforts arround health disparities. And Rita Sharon, who I mentioned before, has for example, described anthropologist clinician Paul Farmer. Some of you might know about his work.

He's been at the forefront of the, at the global level of health disparities issues. And she describes him as a master narrator himself in his own writing. Bearing witness to the trauma of individual patients and also in plotting the broad course of history from points of view of the oppressed.

And so she cites him as an example. And I'll just quote Paul Farmer, who is very concerned with the political economy of health care problems and health care disparities, but at the same time, also argues that stories are very important. And part of his argument is that they're important in conveying the experience of suffering.

Because the, so he says, the suffering of the world's poor intrudes only rarely into the consciousness of the affluent, even when our affluence may be shown to have direct relation to their suffering. Because the texture of dereflection is better felt in the gritty details of biography I introduce stories.

But he goes on to say, that this is not a, merely a matter of being anecdotal, and cites an economist, who I'm sure you're very familiar with, Amartya Sen. Who reminds us of the need to move beyond quote, the cold and often inarticulate statistics of low incomes to look at the various ways in which agency, or what Sen terms the capabilities of each person, how these are constrained.

I also want to move beyond in taking a narrative approach, a kind of an idea that we need to listen to personal stories. I think that's important, but for me, and, and what I want to do in this paper, is think about the way that narrative permeates clinical practice not simply because people are telling or hearing stories, but because there are certain kinds of cultural genres or even archetypes that shape clinical encounters.

And that embody ideals associated with biomedicine as applied science. Supply biomedical hope with possible happy endings to various kinds of disease stories. And run into all kinds of trouble, in the case of chronic conditions. And I want to, so there are three which I'll get to that I'm going to pay special attention to.

You will recognize them all, because they are not special to the medical world, but part of our, part of a cultural imaginary. That is embedded in popular culture and has traveled globally along with biomedicine. One is the idea of healing as a kind of sleuthing or detective story.

Another as a kind of repair story, pairing the broken machine body and a third is a battle. Of course, you know these, because they're familiar stories to all of us. So I'll just talk about them briefly and then introduce how they get played up and played out within actual clinical encounters.

So the idea of healing as a science detective story in the canonical version, you know, the sort of Shakespeare of these archetypes is that part of the canon. That, they, the key protagonists are, are a doctor and the disease itself. The mysterious culprit of medical crimes. The clinician has flew past the task of investigating medical mysteries, identifying the hidden criminal who perpetrates crimes inside a patient's body.

Leaving traces in the forms of symptoms and signs that present puzzles to be deciphered. The analogy between the detective story and this image of clinical care is not an accident. The medical case as a narrative form actually developed alongside the detective story as a literary form. Arthur Conan Doyle, who gave us Sherlock Holmes, was himself a physician.

And the figure of Holmes was inspired by a famous physician teacher of the time, a Dr. Bell, who was supposed to be a wizard of deduction. And whose feats of clinical reasoning were legendary. And we can see a modern day version of this, if any of you have watched the TV show House and we can also see how technology has been has been updated and still to, to do this type of detective work.

When it comes to the ongoing treatment of children's chronic conditions, detective work often depends upon partnerships created between clinicians. This is now talking about our research, and family caregivers. Clinicians will routinely judge when they have parents who can help them in their detective work at home, and ask for this help in detecting symptoms and signs.

Families for their part, try to enlist clinician detectives, not always successfully. For Andrina, if you remember, who took a year of repeated ER visits to finally get a doctor to take her child's illness seriously, and only because she finally picked up her child and walked to the waiting room, into the secretary's office, and said, I'm not leaving.

A year later, right? I'm not leaving until somebody looks at my child. meanwhile, she was labeled in at least the clinical, one of the medical charts I looked at, as either mentally unstable or possibly an abusive parent, which is what she feared. So it can be hard to find a detective.

Rambo Mom loves House. I don't know if you've ever seen this TV show, but he's the, a very cranky doctor. She, this is her hero, this kind of, no bedside manner, but relentless. Okay, healing as machine repair, this biomechanical metaphor gives us a picture of illness in which, and of healing in which nature, society, and the human body can be viewed as an assemblage of interchangeable parts that can be repaired or replaced from the outside.

As a machine, the body is potentially fixable, and this is certainly not an abstract metaphor that permeates clinical practice. And especially certain kinds of specialties, like surgical or rehabilitation specialties, and certain kind of diseases, like heart disease. So, and of course, popular culture. And becomes more and more intricate with new biotechnology, this machine-body relationship.

The war story, which is going to be the one I'm going to kinda focus on, with a couple of examples for the rest of this. As you might tell from Rambo Mom, is a character. In this one, of course again this canonical version. Protagonists are fighting the war against disease, and the body is a kind of site a battle site in which war must be waged.

Like the detective genre, this narrative archetype also arose in the 19th Century, though it has gone through several permutations as understandings of the body have changed. It doesn't merely assign as we know the body a an even a post 9/11 version version for children. So the body here is not merely a passive character.

It too can mobilize resources to come to its own defense. In our study, children as well as parents, become trained in learning to see their bodies as sites of this sort of internal battle. They're recruited by clinicians to serve as assistants in the war. So, in the following example, a hematologist speaks with some enthusiasm about he has made, how he has made a little blood model, little plastic model.

It's kinda like a Pac Man. In order to facilitate his explanation to children of being, and even parents, of being HIV positive. And about AIDS. He especially uses this model when he has to disclose to children that they are HIV positive. In the following exchange, he's decided it's time to tell Tommy, one of the boys in our study, who was nine years old at the time.

He tells Tommy, and he, I, so, this is kind of, the Pac Man here is a bad guy, right? He eats the, the germ. In the following exchange, he tells Tommy that a germ in his body has attacked his white blood cells. He explains that Tommy's white blood cells and T-cells have gotten too low, and that the medications that he's been taking could prevent him from getting sick.

Using this model, he places a round kind of ball thing in its mouth, and it eats it and the model lights up. Very graphic, as the doctor says. Then the hematologist explains, HIV is the germ that attacks and eats white blood cells in the body, but the medicine fights the germs.

When he's done explaining, he asked Tommy if he has any questions. And Tommy has a few. He asks, is what I have worse than sugar diabetes? The doctor says yes. Can friends catch my germs? The doctor: some people are pretty dumb about HIV. They respond like it's a kind of leprosy.

But am I nervous about examining you? Tommy shakes his head. You can't go talking to everyone about what you have. Medicine is so important to keep your T-cells fighting strong. Which cell does HIV attack? Tommy: The T-cell Doctor: Do you have any other concerns? Tommy: I'm stuck on the dying part.

The Doctor: You have more chance of dying if you run out into the street and get hit by a truck. You can't die if you don't get sick first. You won't get sick if you take your medicine. So the doctor's words here reinforce the message that his body will mobilize to defend itself if Tommy does his part faithfully by taking his medicine.

The danger of the storyline, of course, shows up here. If a treatment failed, then the enemy grows stronger. Patients may be subtly blamed, or even blame themselves. From the family's perspective, this canonical image of Biomedicine as battling disease becomes much more complex. As in the detective genre with Andrina, they may believe that they must fight to help keep clinicians in the battle.

Parents may come to see themselves rather than the doctors as the primary frontline fighters, as in the following example. In which one of the mothers, Dottie describes herself as having had to become a Rambo in caring for her severe, severely ill daughter Bessie, who has sickle cell anemia.

Awful disease. And here's a quote from the speech she gave to an, there was a whole sickle cell research day, or a sickle cell day at the hospital where parents and clinicians were, and she was asked to speak, and here's how she described what it was like for her.

And what, how she acted with her daughter. What I do is I get in my Rambo mode. If my daughter gets just the sniffles, I get hyper alert. I grab all my machine guns, all my equipment, guns there to attack that organism or that whatever. I check the pulse, I listen you know, watch her color.

Gotta get out there and just attack if so, if something happens or just really get things in place. And they make trips to the emergency room all the time, because this can become life threatening within a very short amount of time if you're so severely ill. So Rambo you'll recognize him.

And here's the the kind of indiginizing of Rambo. When Rambo becomes a mother. So here's Dottie. That's back to Rambo again. She has her battles. She's trying to persuade clinicians to take her perspective seriously. The weapons that she uses when she visits here. She's here for a second opinion to try to figure out about whether her daughter has acute asthma or not.

She brings her medical records, she brings x-rays, she comes in with a stack that's of, of material to give to this to this doctor to ask him to look at. He puts up the x-rays. And here she's working with her primary doctor, the hematologist. They're both, so here's her daughter in the middle.

They're both separately checking their medical records. She has recruited him as an ally. These are still taken from a video tape and I only have a couple here. But there's, we made stills out of them and the, the body language is perfectly synchronis of this mother and this doctor, as they're trying to figure this out.

There's about ten more, but I couldn't figure out where I put those slides. So, okay. I'll leave it there. Like a ferocious warrior, Dottie represents herself as on the front lines of the battle field. But there's another genre. The genre of the, of the transformative journey. Also a very familiar one, a very culturally familiar one.

That is the dominate genre, the border genre, that the, that is very much the dominate one from the patient and family perspective. In this genre, they emerge as the key protagonist, and it's not that these canonical plots are unimportant of battle and so forth, but from the parent's perspective, they imagine these as essentially subplots within larger narrative frames that encompass personal, familial, and community lives.

So we can see it here. And we can see the mismatch between Tommy's question and the doctor's answer. So when nine year old Tommy hears from the physician that he has HIV positive. And asks if he has any questions, saying he's stuck on the dying part. The physician answers, the hematologist answers confidently.

You have more chance of getting hit by a, I should say truck, by a truck if your medications are taken. That's the, of course, battle story canonically. But it simply neglects the drama that Tommy's question is about. What kind of story am I in, he's asking. He has a mother he rarely sees, but knows is quite ill.

She has AIDS. His initial question is what I have worse than sugar diabetes, not, is not a clinical question, but a personal question. His grandparents are raising him. They're his primary family and at the time of this session, his grandfather was very serious ill as a diabetic. He'd already had a foot amputated and he was in fact, dying.

So, of course from that perspective, the idea that he has something worse than diabetes is missing the story that Tommy is just simply missing the entire genre, that these questions are coming from in Tommy's point of view. I'm

Anne Stevens, the Director of the Center for Poverty Research at UC Davis, and I want to thank you for listening.

The Center is one of three federally designated poverty research centers in the United States. Our mission is to facilitate non-partisan academic research on domestic poverty. To disseminate this research, and to train the next generation of poverty scholars. Core funding comes from the U.S Department of Health and Human Services.

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