"Doing Critical Consumer Research: The Case of Health Care Delivery in Appalachia"

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ABSTRACT

This study uses a critical-emancipatory approach to identify and examine contradictions in the delivery of health care services to impoverished consumers in a rural Appalachian community. The findings of an ethnographic study suggest that the dominant medical discourse is hegemonic and contradicts local interests and forms of life. A case study of a nontraditional form of service encounter, a local mobile health unit, suggests how the dominant health discourse can be destabilized by alternative discourses that are based on the local context and interests. Nevertheless, both the traditional and nontraditional forms of health care create contradictions that can inspire new forms of health care that are less constraining and more just.
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INTRODUCTION

Scholars continue to criticize the field of consumer research for the paucity of relevant research done in the interest of consumers (Andreasen 1993; Arnould and Thompson 2005; Belk 1987; Cohen 1995; Denzin 2001; Firtat 1999; Mick 2004). While a number of critical paradigms exist that seek social change as a goal, these approaches still remain on the margins of the field despite their potential for informing programs of social change (e.g., critical ethnography [Penaloza 1994], feminism [Bristor and Fischer 1993; Catterall, Maclaran, and Stevens 1997; Dobscha and Ozanne 2001; Edwards and McKie 1995; Joy and Venkatesh 1994; Stern 1993], and neo-Marxism [Murray and Ozanne 1991; Hetrick and Lozada 1994; Hirschman 1993], to name a few). This paper seeks to explore critical theory as a fertile approach for enacting workbench programs of social change. Specifically, we examine the delivery of health care services to poor consumers in a rural Appalachian community to demonstrate how a critical approach can improve the lives of consumers.

Part of the challenge of doing critical research arises from the poststructuralist critique by theorists, such as Foucault, Derrida, and Baudrillard, who attack extensions of the work of the Frankfurt School that seek to further the rational project of the Enlightenment (Held 1980; Horkheimer 1937/1972; Jay 1973). Whether it is Habermas (1984) seeking a consensual form of communicative rationality or a critical-emancipatory approach arguing for more rational forms of organization to increase human potential (Held 1980), research that is based upon notions of a universal rational voice are deemed
problematic. Broadly, poststructuralists reject emancipatory goals as modern truth narratives that represent a power relationship that must be deconstructed (Firat and Venkatesh 1995). Totalizing theories that are grounded upon appeals to reason seek to privilege one form of truth narrative over other forms. No one truth exists, but multiple shifting truths are created through various discourses in society. Thus, poststructuralists celebrate dissensus and difference as ways to destabilize truth discourses and illuminate their ideological and epistemological underpinnings (Holt 2002; Poster 1989; Thompson and Hirschman 1995; Thompson, Stern, and Arnould 1998). All discourses are equal and no single reading can be privileged over another (Agger 1994; Francis 1999).

Critical researchers are unwilling to give up on the Enlightenment’s vision of more rational forms of society and attack the postmodern abandonment of the goal of radical social change. From a critical perspective, a science with no particular claim to truth is seen as cynical, conservative, and disabling (Agger 1994). Miles (1999) suggests that postmodern consumer research is overly abstract and intellectual; it is an introspective exercise that privileges theory for theory’s sake at the expense of gathering empirical data that examines consumers’ everyday situated experiences.

In this paper, we are sympathetic to the critiques of both modernism and poststructuralism and seek to affirm the emancipatory aims of critical theory, while minimizing the potential power of totalizing theory to silence marginal voices (Frances 1999; Hanssen 2000; Kintz 2003). If truth and power are inseparable and arise in theoretical discourses, then we must find forms of theoretical discourse that can bring social change without becoming a greater source of oppression (Agger 1994). A growing body of research seeks dialogue and alternatives that can move beyond the impasse
between critical and poststructural theories (Francis 1999; Fraser 1997; Fraser and Nicholson 1990; Hanssen 2000; Thompson, Stern and Arnould 1998).

Thus, this paper seeks to reduce human suffering (e.g., the critical modern impulse of Murray and Ozanne 1991) based on critique that is contextualized to the interests and historical circumstances of small, localized groups (e.g., the poststructural sensitivity of Thompson and Haytko 1997). If suffering is caused by hegemonic metanarratives, then this discourse can be destabilized. Extending the work of Gould and Gould (2003), we examine empirically the dance between social actors’ subjective understandings and social structure and seek to identity fissures and tensions that can be used to forge new contextualized discourses that may alleviate suffering. While this new discourse could itself become oppressive, if it arises from the voices of the participants and reduces suffering, then it is better than a discourse that is imposed from outside (Agger 1994). The critical moment, however, is never-ending and the goal is a justice yet to come (Hanssen 2000).

First, we identify a concrete social problem and explicate the ethnographic methodology employed. Second, we identify and examine contradictions in the delivery of health care services to women consumers in a rural Appalachian community. We find that the dominant medical discourse is hegemonic and contradicts local interests and forms of life. Third, we present a case study of a nontraditional form of service encounter, a local mobile health unit, which shows how the dominant discourse can be destabilized by alternative discourses. While this mobile health service resolves many of the contradictions that arise in traditional medical encounters, new contradictions emerge.
In the final section, we describe potential and actual forms of awareness and praxis (i.e., theoretically-informed action) that arise from the voices of the informants.

**THE CONCRETE SOCIAL PROBLEM**

Research consistently documents widespread disparities in health status, particularly for population segments such as racial and ethnic minorities, rural residents, the homeless, indigent communities, and post-industrial communities (American College of Physicians 2004, Gould and Gould 2003, Hatton 2001, Hill 1991, Institute of Medicine 2003, National Rural Health Association 2004, Villarruel 2004). Not only are these populations at higher risk for illness and death than the national average, but they also face inequities in health care access and insurance (Aday 1993, Shi 2001). Thus, an important social problem is meeting the health care needs of these at-risk consumers.

We examine the localized health care problems of women in a rural Appalachian community, Fairmount County.¹ This community was chosen as the research setting based on the primary criterion of multiple vulnerabilities. Fairmount County has numerous risks that make its residents susceptible to poor health such as rural isolation, adverse economic conditions, and environmental and occupational hazards. We also focus on Appalachian women because they traditionally serve as the primary caretakers and health care decision makers for their families.

**METHODOLOGY**

**Evolving Research Design and Data Collection Techniques**

We employed a two-stage ethnographic methodology. The first phase of the research was designed to gain a socio-historical and contextual understanding of local interests. At this stage, data collection included secondary data analysis (e.g., census data,
regional health statistics), engaged observation at many Appalachian events, focus group
interviews with community women, semi-structured interviews with health care and
social service providers, and participation in a Fairmount County Women’s Health
project (see Appendix A). Data collected and analyzed at this stage guided subsequent
data collection.

During the second phase of the research design, emergent themes were explored.
The first author lived in the community for six weeks and volunteered on the
Healthmobile (HM), a mobile health unit serving the area. Data collection included
engaged observation of the HM and daily community life, informal interviews with
community women, and in-depth interviews with community women and health care
workers.

Research Sample

Forty-four women were involved in six focus group interviews. Purposeful
sampling of groups was employed to represent different risks of poor health (e.g., low
income housing residents, African Americans, senior citizens, cancer patients). Semi-
structured interviews were conducted with twenty-two health care and social service
providers and community leaders to explore the health care of rural clients.

We explored emergent themes in the service encounter through in-depth
interviews with eleven women, five physicians, and a certified family nurse practitioner
who directs the Healthmobile. We employed a judgment sample to gain variability on the
nature of women’s health problems (i.e., few/many, chronic/acute), the extent of contact
with the health care system (i.e., high/low), and resource availability (i.e., income,
insurance, and transportation). Finally, engaged observation on the Healthmobile
involved contact with dozens of local women.

Data Analysis

Interview and focus group data were tape recorded and transcribed. Field notes were used as the primary method of recording engaged observation. We employed an emergent approach to analysis in which analytical categories evolved and expanded as the data were iteratively analyzed (McCracken 1988; Thompson 1997). We specifically sought out tensions or contradictions that existed between the subjective experiences of the informants and the social structures (Murray and Ozanne 1991). Several iterations were needed to challenge, expand, and refine these understandings.

THE SOCIO-HISTORICAL CONTEXT

The Appalachian region and its people face a long history of stereotyping, including portrayals of Appalachians as ignorant, simple, traditional, clannish, inbred, and prone to feuding (Billings, Norman, and Ledford 1999; Speer 1993). Such stereotypes have contributed to a view that Appalachians are victims of their own cultural inadequacy. This “culture of poverty” perspective holds that individual deficiencies and a defective folk subculture passed down through the generations are the root causes of impoverishment in Appalachia (Cattell-Gordon 1990; Ford 1967). Such an ethnocentric position ignores the diversity of Appalachia, privileges mainstream values, and deflects attention away from structural explanations of poverty (Billings and Blee 2000; Ryan 1971). For example, Couto (1994) implicates businesses’ role in bringing about regional poverty; he coins the verb Appalachianize to mean extracting valuable resources in such a way as to create a substandard economy.

Appalachian people have struggled for years against outside economic and political forces, battles with the coal industry, and the continuing struggle to get the
government to invest in education, health care, and the environment (Billings and Blee 2000; Couto 1990, 1994; Fisher 1993). Within Fairmount County, community members regularly joined forces to oppose threats from outside the community. Residents of the Oakwood community, for instance, successfully fought against their town being bought by a coal company and were able to protect their homes.

Fairmount County is plagued by poverty, unemployment, and substandard social capital investment. The percentage of county residents living below the poverty threshold is 21.3, compared to the state percentage of 9.6 (U.S. Census Bureau 2000). The 2003 average unemployment rate was 14.5 percent, over 3.5 times the state rate of 4.1 (U.S. Bureau of Labor Statistics), and the area is economically depressed with few new employers. Those industries that have located to the area in recent years are light manufacturers, offering jobs that are part-time and low paying with few or no medical benefits. Roads are windy and poor, housing is overcrowded and substandard, the air and water are contaminated, and many of the jobs are hazardous.

Well ah, until the sewer system is put in Walnut Bottom here, we have very poor, uh, sewage disposal. And, it’s a thousand wonders more people hadn’t had typhoid or a lot of things.... Well it goes right into the creek bed and then it goes to the river. And out here on Main, right out here on Main Street, sometimes that smells so bad that I can smell it on my front porch. (Focus Group 3)

Well, at the sewing factory you breathed the fiber for the materials, and that’s not good. They didn’t have any air conditioning, so we stayed hot all the time in the summer time. And they locked us in. We went in the door, locked behind us, and the only time we could get out was when they unlocked the door to let us out. If there was a fire, how would we get out? Because they had to push a button from the office to open the door. I think it was more of a hazard than it was anything else. (Interview with Elaine)

Life in a poverty-stricken community means that Fairmount County residents lack basic necessities — adequate shelter, clean air and water, and safe jobs.
Fairmount County is federally designated as a medically underserved area, with a physician to client ratio of 1:2937 in contrast to the national average of 1:704 (State Primary Care Association). Six primary care physicians practice in the county and people travel long distances for specialists. Yet rates are higher than the national average for heart disease, chronic obstructive pulmonary disease, pneumonia, and black lung disease (Regional Health Planning District Report). County residents also experience higher rates of cervix, breast, lung, and colo-rectal cancers, as well as suicide.

The United States health care industry is characterized by a tiered distribution system based on ones’ ability to pay — a private tier serves the more affluent and a public tier serves lower income groups, welfare recipients, and the uninsured (Sandy and Schroeder 2003). The informants in our study experience the public tier of the health care system and the associated difficulties and disparities of public medicine.

When I [gave birth to my son]...I began to hemorrhage.... I can remember the doctors was asking the nurses or whoever it was at the registration table; they were asking my mom questions about who I was, do I have insurance, or do I have this or do I have that. And one doctor came up and said, ‘We don’t have time to ask all these questions,’ that I immediately had to be in the room. And then I’m sitting there losing blood and they are trying to figure out how they are going to get paid. Then you have them people who they knew had insurance who were admitted immediately. (Interview with Fran)

The uninsured women are sometimes refused services, for instance.

In summary, disparities in health outcomes and access are widespread and Fairmount County is medically underserved. The women lack economic resources since unemployment is high and existing jobs are part-time, low paying, and lack insurance.
CONTRADICTIONS

The Dominant Medical Discourse

The dominant medical discourse that pervades health care encounters was at odds with the health care needs of the Fairmount County women. Physicians are trained and socialized into a curing model of health care, which focuses on the disease in isolation of the patient. The historical roots of this orientation lie in the medical breakthroughs of the 19th century, which vindicated the metaphor of the body as a malfunctioning machine and the germ theory of disease (Conrad and Schneider 1986). The doctor is a “body mechanic” wielding the newest technology on the prone body and focusing on what is seen and measured instead of what is felt and experienced (Evans 1993).

Nevertheless, the curing model ill prepares the physicians to deal with the realities of rural medicine or the needs of vulnerable consumers. In the following sections, we identify contradictions that emerge in the health care encounters. First, the doctors were trained to provide acute, specialized care that was dependent on the latest technology — a type of care that was far removed from the realities of practicing to the poor. Second, in the service encounter, the dominant physician co-creates a submissive patient with little to no voice. Third, while the physicians and health care system emphasize patients’ individual responsibility for their health, our data illustrate the need for corresponding attention to structural explanations.

The Physicians’ Training and the Experience of Rural Practice

The curing model of health care permeates Fairmount County physicians’ interactions with consumers. Consistent with a disease orientation, physicians tend to objectify consumers as body parts, diseases, or “cases” — not as living, breathing human beings.
Before the hospital was built, they would bring all acute cases here. We’d see acute, uh, MI, cardiac arrest. (Interview with Dr. Cooper).

An awful lot of physicians in general are not oriented towards listening — they’re problem oriented — ‘let’s fix whatever is wrong and then go on.’ (Interview with Dr. Thomson)

Doctors see consumers as problems to be fixed and view the service encounter as an engaging intellectual exercise. Dr. Bell described patient interactions as an opportunity to exercise his training and expertise.

We don’t have enough equipments, you know, enough manpower to take care of the patient and exercise the knowledge that we have about taking care of patients…. a lot of us are capable of doing things you know based on our training, but the equipments are not available…. [One constraint of working in this area] depends upon what the hospital can furnish you, to exercise your ability to uh, to uh, uh exercise your knowledge of medicine…. Sometimes you waste your training you know because you are not furnished uh equipment, supplies, you know that you need to take care of the patient. (Interview with Dr. Bell)

Consistent with their medical education, the physicians objectify illnesses into problems to be solved, which may also shield the physicians from the emotional demands of the job.

The physicians are also socialized and educated in specialized, high-tech care, and their training is based on access to resources and technology. However, the skills needed to practice rural medicine are underdeveloped. Physicians discuss the demands and frustration of working with limited resources and equipment.

I think it is a challenge, you know, because as I mentioned to you about the limited resources that we have. And uh it is a challenge to diagnose a disease, especially a rare disease you know when we don’t have the sophisticated equipments that bigger centers have. (Interview with Dr. Smith)

You do not have, uh, good medical facilities, laboratories…. What uh, for more specialized cases we cannot do uh cardiac catheterization. For major surgeries and neurological cases, we have to send all of them out. (Interview with Dr. Cooper)

But access to sophisticated services and specialists is often irrelevant because many local
residents cannot afford such treatments.

The other difficulty . . . is really when you want to refer a patient... you want a consultation, they cannot go, they don’t have money. It’s just, I have to send them to Sickersville, four to five hours driving because it’s a university program. Some of them, very few go, and the rest just prefer to stay home, not seeing the consultant because they don’t want to go to Sickersville because they don’t have a car or they don’t have the money to pay for the gas or they don’t have the money to pay for the doctor. This is a very difficult thing. (Interview with Dr. Adams)

While the doctors are concerned and care about their patients, their medical training ill prepares them. For example, about 70 percent of deaths in the U.S. are from chronic disease, yet medical schools focus on acute problems and largely ignore important issues such as preventive health care, lifestyle education, and the impact of social factors on health status (Cotton 1991, U.S. Department of Health and Human Services 2004). The physicians’ specialized training for acute care inadequately prepares them to deal with preventive care and the multitude of roles expected of them working in an impoverished community.

All the medical practitioners in this area are geared toward incident treating, rather than preventive care. . . . I don’t know of any other single practitioner that does this sort of thing. That spends time with not only the women, but other people, stressing preventive care. Other than the health department. (Interview with Dr. Waters)

You have to be here a psychiatrist, you have to be a cardiologist, ophthalmologist, here in this area it’s because people cannot afford seeing a psychiatrist. Even if they have Medicaid for psychiatrist, they don’t see Medicaid for somebody I don’t know. So really it’s really you have to really take the you know psychiatrist’s role and the cardiologist’s role, you have to do a lot of things here to, to, to you know provide these people with reasonable care. (Interview with Dr. Adams)

Thus, a tension looms because the dominant curing orientation socializes doctors into specialized, technology-based, problem-centered care; however, in practicing rural medicine, this care is often unavailable, sometimes unnecessary, and usually
unaffordable. Instead, the experiences of our physician informants suggest they need to develop new general diagnostic and interpersonal skills unsupported by advanced technology.

**Authority and Voice in the Service Encounter**

Consistent with the curing model, the health care system privileges the physicians’ authority; the physician is dominant and the patient is subordinate. For instance, Fairmount County physicians viewed themselves as the primary supervisor of the consumer’s health.

When I see a patient here, I, when I discuss things I tell them, I usually tell them that for your own good you should follow up with one doctor. You need to have a monitor of your health. (Interview with Dr. Smith)

It’s a doctor’s job to go ahead and investigate more and get to the depths and the bottom of what this woman is going through or has been going through. (Interview with Dr. Bell)

The good physician gives, while the good patient receives.

I think the best [service encounter] is when you have somebody you know uh that is almost helpless you know, especially those that are dying and you can see their face lightens up and then they start saying thank you for saving my life, and then the family comes and hug you and talk to you and say you’ve done a good job. That’s the best. (Interview with Dr. Smith)

We can communicate easy with people here [in Fairmount County]. I mean they’re, one thing about them it’s, they’re very kind people, they’re very loving people. And uh, uh, they appreciate what you do for them, you know they are grateful and so on. Um they listen to you, they come to you looking at you like you are a big shot, you are someone who will help them. So this attitude on their part is very nice. (Interview with Dr. Adams, italics added)

Moreover, the physicians enjoy the aid and comfort that they provide and the status their skills bring them.
Women frequently reported that doctors expected deference to their authority:

“they get very upset when you question them” (Interview with Fran). Similarly, some physicians resisted requests to explain their decisions or recommendations.

I have always been one to ask, ‘Well, why are you doing this?’ You know, if it was my child. I think [any patient] should have that privilege. And the doctor should be willing to ... answer your questions, you know, [such as] ‘Why are you drawing blood, or why do you want to put him through an x-ray? Isn’t that dangerous?’ [But this doctor I worked with] would come back with ‘If you doubt my ability as a doctor I will more than happy to refer you to somebody else.’ .... Well, that would make me so mad because there is the nurse going in behind him and you are going to have to calm this mother down.... Just there again, ‘You have no right to question me as to what I am doing. ‘I’m the doctor, I know best’ deal.’ (Interview with Kathy, italics added)

But our doctors, my problem with our doctors is they don’t explain anything to you. They, they’ll x-ray you and they’ll pap smear you, and they never tell you nothing what’s going on. To me they seem to get uh, awfully upset when you’re asking them what is it they doing. They don’t like to explain nothing to you. And then you ask them what they giving you medicine for and then, you don’t know what they writing. You don’t know what they writing. You may, they may tell, they may not. Sometimes I have to ask the pharmacy, ‘What was this medicine for?’ (Focus Group 1, italics added)

Doctors maintained and reinforced their expertise by resisting challenges to their authority. The women were expected to support this authority through their acquiescence.

Much of physicians’ power lies in their ability to control the service encounter during the traditional clinical interview (Kleinman 1988; Waitzkin 1985, 1991). Doctors control when and how consumers participate in the service encounter, with little room for patient involvement beyond answering the doctor’s questions.

Usually I just, just interchange, I ask questions and they answer and if there is any problem with uh tests you know they ask questions and I try to interpret tests for them... In medical school they do uh have courses just on patient interviewing and how to interact with patients. But that’s mostly just to get the information out of them. Like if somebody comes in who says, ‘I’ve got a headache.’ Just to get them to tell you, describe the ache, how long it's been hurting, just all the symptoms. (Interview with Dr. Thomson)
The quest for diagnosis drives the encounter. Doctors obtain enough information from the patient to facilitate diagnosis, often ignoring other information. The women express that the physicians oversimplified and withheld information based on the assumption that the women are ignorant and unable to understand or participate.

Most of them [doctors] automatically, I think, assume that most people here don’t have the intelligence to comprehend what they are telling them. So therefore, they will completely omit it [information]. Most of the people that I talk to here, just normal everyday people, don’t even know what their diagnosis was.... And that’s sad. And then their [doctors] insult their intelligence. (Interview with Rhonda)

Like I say they, they run you to death and like I say never really tell you anything. And I say ‘What about the test, what did the test say?’ ... [The doctor said] ‘It may be parasites in your stool. It may be blood. It may be something that’s causin’ this,’ you know. They passed it off as a gall bladder; may remove the bowel or something.... But, ah, he never mentioned the tests, never. And I said, ‘Well, what did the tests show?’ ‘Oh, they all came back real good.’ That’s the only thing he said. (Focus Group 1)

From the women’s perspective, they seek to participate in the service encounter, but are unsuccessful when they find that their contribution is ignored or minimized.

They [physicians] will not really listen to or examine you. They tend not to... ‘Well, ah what’s, what’s the problem?’ They’ll write (a prescription) before you, you know right then you’re trying to explain it, say your back hurt, what it is you know. (Focus Group 1)

The women also feel minimized when providers trivialize their needs and concerns, or their knowledge of their own bodies.

I know . . . because my body has changed, and I know I’m going through the change [menopause].... Because you know when your body changes, like your period comes on one day and then it goes off, that’s a change. When you’re crying when you never cried before, that’s a change. So, that’s something. That, that’s, that’s means you’re going through the change, that’s a change. And then, but when you tell, talk to a doctor and he says ‘you’re stressed, that maybe it’s stress, you work too much or something like that.’ He don’t know nothing. (Focus Group 1, italics added)
Discounting the doctor’s words or actions was one way that informants resisted the doctor’s authority and reasserted their own.

In summary, the physicians are trained to view the service encounter as an intellectual problem to be solved efficiently. Their patient loads are high and they seek to apply their knowledge to solve efficiently the problem at hand. The women feel diminished in the encounter when they are unable to be active participants and their voices are silenced.

The Accountability of the Patient versus the Social Structure

Despite the realities of rural Appalachian poverty, the physicians frequently emphasized the women’s accountability for their own health problems. Providers attributed poor health outcomes to the women’s inadequate education, non-compliance with doctor’s orders, and failure to engage in preventive care or adequately use existing services.

I think most of the problems about health care in Fairmount County, the access to medical care is here. It’s just a matter of getting in and taking advantage of it. It’s always a problem getting people to come in for the pap smears, mammograms and just kind of keeping, keeping regular check ups. [R: Why do you think that is a problem?] . . . . If something is not bothering you, and a lot of times when you see a patient for just, like for a pap smear, they are not having any symptoms. If something is not bothering you then they try to put it off. And it’s usually not financial, it’s just, just they don’t want to go to the trouble of getting up and trucking off to the doctor’s office and spending half the morning there. It’s partly education, you know . . . . You have got to keep after them to come in and do their pap smears. .... I think they could come in. Most people in the county have some kind of insurance, Medicare, Medicaid, something like that. (Interview with Dr. Thomson)

This doctor suggests that failure to get adequate health care is an individual choice alone, and he discounts the role of economic constraints and lack of insurance. Similarly,
another physician blamed women for not getting pap smears and mammograms, but these services are poorly available in the county and unaffordable for many of the women.

Most women don’t bother to get regular pap smears. Most people don’t bother to have baseline mammography and keep up with it, or do self exams. Prevention is just not part of their orientation, they don’t do it.... There’s still a tremendous population of women especially who don’t bother. Don’t bother to ever come for a checkup if there’s nothing wrong. (Interview with Dr. Waters)

This common practice of blaming the women for their health care problems suggests that the physicians do not fully acknowledge or understand the impact of social structures on the women’s health and ability to get health care.

Some physicians did recognize and identify structural barriers to health care access, yet they still placed the primary blame on the women.

Mammograms are poorly available for the women, but even at that, I doubt that as many women receive them as probably could get access to them. There’s a need for women to learn about what the recommendations are. In many cases the service is available to them, they have to use it...have to take advantage of them. (Interview with Dr. Robertson)

In another example, the physician recognizes that women sometimes cannot afford to buy prescriptions, but nonetheless cites poor compliance as the main problem.

The money. They cannot really buy the medicine. You, we have some you know supplies, some samples we give them for two or three days and what happens is just go and I’m writing a prescription to finish taking the medication from the prescription. They go ahead the take the samples and stop. And then you end up having more problems like you know resistant and infection you know. Patient comes here with uh sinusitis you know you give her like a few samples of Augmented and tell her like take five more days. No he takes just a sample and forgets about it. He ends up having chronic sinus infection because he did not take the whole course. That’s one thing. Two is as I told you compliance. People it’s, they don’t comply with taking medication you know some of them do but you know what I found is that most of them they don’t, it’s just they don’t stick with taking their medication. (Interview with Dr. Adams)

Consistent with this tendency to blame the women for their problems, the physicians all stress education as the most important solution for improving health care
access and status.

The main thing in this area is education. Educating the uh female population on what uh examinations they have, what uh they need to have uh periodically like a pelvic exam, pap smear, mammogram. (Interview with Dr. Cooper)

The doctors’ proposed solutions to improve health care emphasize the importance of changing the consumer’s behavior and increasing education; structural changes are rarely cited.

In contrast, the Fairmount women are frustrated and disempowered by health care solutions that do not consider their daily realities.

I hear repeatedly from the women’s stories that many providers, particularly physicians, do not understand them and their lives. There are many variations on this theme. For example, today a client told me that a doctor ‘prescribed $90 worth of medication and had no clue that I wasn’t about to get that filled because I can’t afford it.’ I asked her if the doctor had discussed other ways to help her besides with medicine and she said ‘no, he barely talks to me much less understands what my life is like.’ Another prevalent example women have shared is providers’ telling them to develop better eating or exercise habits. Women often follow such anecdotes with a comment like ‘that doctor just don’t understand what it's like’ or ‘that's easier said than done.’ That is, eating healthily and finding exercise outlets in Fairmount County are difficult (e.g., limited incomes, transportation,....; limited selection of fresh produce in grocery stores; few healthy choices in restaurants; few walking trails). (Fieldnotes)

The women take active measures to manage their health care needs and are knowledgeable about preventive care and education. Community women engage in and understand the importance of healthy behaviors such as diet and exercise for staying healthy.

[I] try to do exercises and not eat no cholesterol and you know things like that to keep from building up any cholesterol in my veins or arteries and things. (Focus Group 3)

I take a lot of vitamins, of all kinds. My kids tell me I’m a vitamin fanatic.... And I normally exercise.... Try to eat right. (Interview with Fran)

Informants also recognize that some of their current behaviors are unhealthy and need to be
I’ve been on a diet, but that’s a yo-yo situation. Up and down, up and down. And, which I know that’s not no good way to do either.... (Focus Group 1)

In addition, self- and peer education is a prevalent health management strategy.

Informants actively seek out health-related information.

I read all the time. I read almost anything on a medical things. (Interview with Rita)

They [doctors] didn’t explain things [about childbirth]. The only way that I knew what was going on was that I took a childbirth class. Me and my husband did. And we learned a lot there. But as far as them explaining anything, they didn’t. If it hadn’t been for class I wouldn’t have known what to expect. (Interview with Elaine)

However, the women in Fairmount County go well beyond self-study and actively educate one another and their families about health matters.

I think that one of the things that is really important, ah, the ones of us that have had cancer, to talk to other people about the mammograms. Now, I have talked to sooo many people. Now there’s a one of the ladies that’s in the other room here, ah, about a month before she found out she had cancer in both breasts I had, she was down to the nursing home with her grandmother, and we were down there visiting, and she didn’t know I had had cancer, and I said, you know, if you haven’t had a check up, I said, please go have those mammograms, it’s so important. And I could not believe, and I’d say in a month’s time, we got word in our church that she was having, that woman had to have both breasts removed. She had gone on and had the mammogram, you know, Mary. And uh so you know, I felt like just through me maybe tellin’ her it was so important, that coulda saved her life. And I felt so good that I had went ahead and told her how, and now everybody I tell them, you know, please get those mammograms, it’s so important. It’s very important. (Focus Group 5)

The women take active measures to manage their health care needs within the context of the structural barriers they encounter. They identify structural changes when they make suggestions for improvements in health care.

Where these clinics operate, where these clinics are open, say, like 24 hours a day, you can walk in off the street without an appointment.... Nine to five don’t get it all the time. That’s why these people end up in the emergency room. (Interview
with Rhonda)

And as far as women’s health is concerned, I think there needs to be more mammography screenings and I think it needs to be… income based. (Interview with Kathy)

Thus, a contradiction exists between the health care system’s and physicians’ emphasis on patients’ individual responsibility for their health, and the women’s broader account of the influence of both individual and structural factors on poor health.

Summary

The curing orientation is a form of decontextualized knowledge that suggests that health issues are narrowly defined medical problems to be fixed by physicians welding specialized technology. When this orientation is enacted in the service encounter, the medical encounter becomes a one-way encounter in which doctors have the power to narrow the interaction so that any needs beyond the immediate medical problem are ignored and the women are relegated to the role of passive consumer. The service encounter is a dehumanizing experience for the women because their emotional and social needs receive little attention, the economic reality of their daily lives is disregarded, their knowledge is devalued, and their active role as managers of their health is overlooked. Thus, the curing metanarrative generates a set of discursive practices that entrap and blame the women in Fairmount County; that is, medical problems stem from biological causes and poor individual choices. As such, medical solutions will arise from the education of these blameworthy individuals. This discourse is silent on the social, economic, and political causes of poor health and mute on structural solutions.

The curing orientation as a type of knowledge and set of social practices constrains the women consumers. The Healthmobile arises as an alternative service
encounter that seeks to foster forms of empowering discourse based on sensitivity to the women’s localized interests. The HM resolves many of the contradictions that are found in the traditional medical encounter. Nevertheless, new contradictions arise that can be sources for new forms of health care.

**THE HEALTHMOBILE**

The Healthmobile (HM), a 28-foot Winnebago, is a mobile health clinic serving Fairmount County. The HM’s main services are preventive and primary care, provision of medication, provider and resource referrals, and counseling. All services and medications are offered free of charge. The HM is sponsored by a local Catholic hospital and funded primarily through grants, which are supplemented by the sponsor and donations. Local physicians donate surplus drug samples, and clients make voluntary donations to help purchase gasoline and medicines.

The HM is staffed by its Director, Sister Kay, a certified family nurse practitioner and Catholic nun; Andrea, a registered nurse; and Christina, a volunteer. Andrea and Christina are Fairmount County natives and Sister Kay has lived in the community for over 20 years. Much of the care is provided in a group setting since few patients choose to be examined privately. About five to six clients can sit at once in the primary service area, so health care is often delivered with other clients present.

**General Caring Treatment that Emphasizes Self-Care**

The Healthmobile provides general preventive and primary care that meets an important need since traditional health care delivery focuses on acute care. Medication, monitoring, and screening tests are the most commonly used preventive services.

A woman on the bus today needed heart and ‘high blood’ medication. She had been doing without her medication for a while because she said ‘My last Zantac
was $89 so I quit getting it. That’s out of my reach.’ She said ‘I met a woman yesterday who everything she draws goes to medicine. I was almost like that—paying more for medicine than for groceries.’ She was thankful that the HM can help provide her medicine because she cannot afford to pay for it every month or to go to a doctor for regular monitoring. (Fieldnotes)

The HM reduces traditional health care costs by providing mobile care and free services and medicine.

During the health fair we did at the garment factory, I mean some of those women hadn’t had a pap smear in 10 to 15 years. So it was a good opportunity for them to get it done because they can’t take off work, and like I said, most of them don’t have insurance and can’t afford to pay for it. (Interview with Christina)

The free samples they give out [on the HM] are so needed. Sometimes I have done without ‘em [medications] for I haven’t had the money like to get the medicine. (Focus Group 1).

The HM also promotes and facilitates self-care. Sister Kay sees the health care system as encouraging physician dependence and she seeks to help people to “understand their own bodies and take care of themselves and maintain an optimal environment for their families” (Interview with Sister Kay). Clients maintain their own personal health data cards for monitoring blood sugar and/or blood pressure readings. Sister Kay also shows clients how to do her own physical therapy when they lack resources.

HM workers also support and advance healthy behaviors and self-care. However, clients are not lectured on their responsibility to engage in healthy behaviors. Rather, such discussions are creative brainstorming collaborations on strategies to incorporate healthy behaviors given the realities of rural poverty. For instance, HM providers and consumers share information on where to find the lowest prices on fruits and vegetables, how to cook these items in tasty ways, and how to fit more exercise into one’s daily routine.

Similarly, the HM staff members suggest simple, affordable treatments that
people can do themselves: “We try to offer remedies that people can actually use given their severe lack of resources” (Interview with Sister Kay). Some simple remedies include warm tea with sugar to help calm the stomach and increase energy, hot water with sugar to help push gas, and vinegar or cold tea to relieve sunburn. Thus, the HM staff suggests low cost/low technology treatments, when they are viable, that are sensitive to the consumers’ economic and social context.

The HM workers employ a caring approach to each client by treating the whole person, including her experience of illness. Treatment extends beyond medical needs to include family dynamics, financial and transportation obstacles, feelings, and individual needs.

Hannah came on the bus to talk about her thyroid problem and how it had been giving her so much trouble lately. She detailed how she had been weak and low on energy, her bones hurt, she was having lots of headaches and nervousness, and was having trouble eating. She was a very skinny woman, pale, with dark and sunken eyes — she looked malnourished and completely exhausted. Kay asked her if she had given any more thought about going to [the university medical center] for surgery. Hannah said no, that she couldn’t. Kay very lightly encouraged her to go, suggesting that summer is a good time to go because travel would be easier, and cautioning her that if she waits too long she might have a crisis and that would not be good for her or her family (husband and two boys). ‘Those boys need you,’ she said. Andrea also gently said to Hannah that she takes such good care of her family that she forgets about herself and needs to take care of herself. All three staff members talked with Hannah at length, empathizing with her daily struggles. She seemed comforted when she left. The staff later told me that Hannah’s reluctance to have the procedure done was driven by fear, family problems, and transportation difficulties. Her husband is not very supportive and even if he did support her having the procedure, Medicaid would only pay for her costs. (Fieldnotes)

The staff sees Hannah as an individual struggling with many obstacles — her medical condition is just one of her problems. The workers are aware of and sensitive to the daily struggles of living in poverty and how this impacts health and possible health care solutions.
Client-Centered Care

The HM staff provide client-centered care by creating a comfortable setting and fostering an “etiquette of equality.” They consciously cultivate a low-anxiety, informal, welcoming atmosphere.

The environment on the HM is very open. Clients can talk about anything and, with few exceptions, the women are comfortable opening up. For example, recent topics have included the stress of coping with a hyperactive child, the trauma of being sexually abused, anxiety about losing sexual desire, anxiety about a young relative touching herself inappropriately, and fears about an upcoming surgery, to name a few. From what the women tell me, they would not be inclined to discuss such sensitive topics with other providers, but the HM staff makes them feel comfortable enough to do so. (Fieldnotes)

The care given in these service encounters affirms three egalitarian norms: personalization of interactions, minimization of social distance, and equality of access to treatment (Fiene 1990, 1993). Care is personalized by asking specific questions about the women’s life and family and through the expression of genuine concern.

Kay held Alice’s hand while Alice was talking about how scared she was about her upcoming tests for cancer. It was a really comforting moment. (Fieldnotes)

The HM staff actively minimizes social distance by using first names. Distance is also minimized by providing thorough explanations, avoiding complex medical jargon, and letting women explain problems in their own terms.

As the woman left the private exam area after discussing her problem with Kay, she said ‘She told me more than the doctor told me.’ (Fieldnotes)

Listening is one of the best things you can do. Just let people talk. Often they can determine their own problems or come up with their own solutions. Lots of times, talking it out has its own healing power. (Interview with Sister Kay)

Active listening and open-ended questions are prevalent staff practices that contribute to the client-centered nature of health care delivery on the HM. Everyone is treated equally and receives the same services. Consumers are given as much time as they need, service
encounters are not rushed, and clients do not feel diminished.

She (Healthmobile nurse) gives you good advice and explains things to you. She’s somebody you can talk with. You can tell, tell her what hurts you, and she’s quick to talk to you about that. (Focus Group 3)

**Empowering Solutions**

Health care solutions proposed by the HM eliminate or reduce many *structural* disparities in health care access. In addition to offering free medicine and services, the HM workers increase access by helping clients negotiate resources that are available to low income consumers (i.e., indigent patient assistance programs that supply free medications). HM staffers find services for clients who cannot afford them.

Now Sister Kay, she pulls some strings and she gets you in places to get things done. Like a mammogram and things like that. Ain’t no way, if you go dry and you draw very little — you can’t pay 200 or 300 dollars to have a mammogram.... She finds something that you need. (Interview with JoAnn)

The Healthmobile reduces provider/service distribution barriers. By traveling to area communities, the Healthmobile decreases transportation barriers to access that stem from misdistribution of providers as well as rural isolation and limited consumer resources.

The Healthmobile. They are helping a lot. They go to the places where most people who cannot come to the clinic, they go to them. (Interview with Dr. Cooper)

Home visits are made to chronically ill clients, to follow up on patients after hospital discharge, and to attend to clients who lack the means to get to one of the HM stops.

Kay is just like a, I just call a little traveling Gypsy.... To be honest, I don’t care what kind of weather, if she’s in town, if she has not gone anywhere or anything, you call her, give her about five minutes, tell her what’s wrong with you, give her about five minutes, she is up here. She is right up here, trying to help you, trying to doctor them all. And I thank God for her many a time. Cause the last time I had the flu, I mean I had it so bad to where I couldn’t, oh, I had it so bad I didn’t know what to do and I knew I didn’t have the money to go to the doctor. I didn’t have
the money for the medication, so I said, well, I’ve got to call Sister Kay again. And she came up and she gave me. (Interview with Paula)

The only home health service in the county is based on one’s ability to pay.

Building skills is another important solution that empowers the Fairmount County women.

A client today was distressed about her medicine. The heart specialist in Ellet City told her he could not do much for her condition, but he prescribed medication as a trial measure to see if it would help. It did not. The doctor encouraged her to keep trying, and she did not wish to do so. She told Kay she was reluctant to tell the doctor her desire to stop the medicine. Kay encouraged and empowered her to be more assertive and ‘tell the doctor what you want, that you want off this medicine.’ The two of them discussed at length strategies to accomplish this task. They asked Andrea and Christina for input, too, which was gladly provided. The woman thanked the staff repeatedly and said the help they gave her was just what she needed—someone to help her build up the guts to tell the doctor she was getting off the medicine. (Fieldnotes)

Thus, the HM staff helps this woman to build her confidence and assert her needs. The HM staff regularly work as partners to solve the women’s problems.

This skill building on the Healthmobile extends well beyond medical issues, however, into building life skills.

The Healthmobile supports families through education and early intervention in the areas of aggression and conflict management, budgeting, and maintaining a healthy family unit. This parenting assistance is built on principles of 1) enhancing self-esteem by emphasizing progress and 2) educating parents about the development stages of children. (Healthmobile grant application)

These practices highlight the broad, holistic view of health that HM staff members support. Health is viewed broadly as well being.

Finally, community members are empowered through the symbolic ownership of the Healthmobile. While HM services are free, donations to help purchase gasoline and medicines are accepted. }
treatments. But the very safety of the HM may keep the women from seeking necessary care in the uncomfortable techno-medical world. Moreover, are the home remedies and self-therapy good effective alternatives or are they the only option for impoverished women and a charity-based health service? The success of the holistic caring approach could even be used to justify greater cuts in funding to rural areas for specialized care and technology-based medicine.

**ENGAGING IN CONTEXTUALIZED SOCIAL CHANGE**

One path for social change is to challenge social actors’ awareness of their lived condition. Four concrete actions were taken to disseminate research findings to the community to challenge social actors’ subjective understandings. Given that the findings are based on the social and historical circumstances of the informants, they can be used to guide theoretically informed programs of action (i.e., praxis).

First, the results were distributed to research participants and community members who requested the information. Second, one of the researchers organized a community gathering to share and discuss key findings. Third, the cancer survivors’ focus group experience increased awareness of the women’s shared concerns and led to the formation of a support group. Fourth, a “readers’ theater” play about Appalachian women’s health care struggles was written directly from the project data. Fairmount County women presented this performance on many occasions to a wide range of audiences including community members, local and state government leaders, and local and state health care and social service providers. Thus, rather than dictating a single solution, the dissemination of the results allows the informants to forge their own solutions.
Actual and potential praxis interventions also arose from the study. Writing grants to support alternative forms of health care delivery was one form of actual praxis. One of the researchers assisted Healthmobile staff members in writing grants to obtain new equipment and expand existing services. The following are other potential examples of theoretically driven interventions. The proposed solutions vary in the extent to which they seek to alter social structures (e.g., medical education, community-based programs) or social understandings (e.g., physicians’ and women’s perceptions).

**Both acute and general care is needed.** Mobile health units are relatively inexpensive in comparison to permanent facilities, have the advantage of adapting to changing local community needs and social context, and can reduce both cost and provider distribution barriers by bringing care to the communities and offering free and/or reduced fee services. However, mobile care cannot be promoted at the expense of acute care. The team concept also has merit for improving general and preventative care. For example, a team with a nurse practitioner, a nutritionist, a social worker, and a volunteer could help fill this need. Such a solution would be more cost effective than the doctors spending time on the practice of general medicine in which they are not well versed. Health care teams can reduce fragmentation and duplication of services, and lead to more comprehensive, “whole patient” care by bringing to bear different expertise and orientations on health care problems.

**The communication gap between clients and physicians** could be reduced by altering the structure of medical education to stress understanding the social context of consumers and valuing consumers’ knowledge and experiences. Interpersonal skills training for physicians, such as active listening, might improve the service encounter for
their clients. Interactions that encourage the consumer into passive roles are not in the interest of generating good health outcomes. Without the participation of the consumer, diagnoses may be inaccurate and treatment recommendations may be misunderstood. Increasing the number of mid-level practitioners and patient advocates is another possible solution. Mid-level practitioners are trained in routine care and psychosocial issues and have better communication, interviewing, and counseling skills than physicians (Campbell et al. 1990). Patient advocates could help consumers gain access to resources, serve as interpreters to help consumers understand physician recommendations, and negotiate the complexities of the health care system.

The women of Fairmount might also improve their ability to get their needs met in the traditional health care setting. Our research found that physicians viewed themselves, not consumers, as the primary monitors of health. Women could be trained to monitor their own health outcomes, such as tracking their blood pressure and keeping health journals. Health care solutions could focus on developing and empowering active consumers. Women could serve as peer educators or be trained as patient advocates. In addition to educating women on illnesses and their treatment, skill development would be crucial, such as negotiation, leadership, and assertiveness training. Solutions are needed that increase consumer involvement and are sensitive to the consumers’ resources (Lee, Ozanne, and Hill 1999; Roth 1994). To the extent that consumers take responsibility for their own health, they are empowered. However, considerable social acumen and skills are needed to resist traditional health care narratives and assert nontraditional views (Thompson and Troester 2002).

**Increasing community empowerment** is an area ripe for exploration. Fairmount
County’s strong sense of community, history of struggle, and norms of egalitarianism are resources that could be leveraged. The community could promote wellness through education (e.g., videos and speakers), support groups (e.g., health discussion groups, exercise classes), and outreach programs (e.g., phone calls during times of convalescence.) Working together to teach and learn from one another resolves the tension between the health educator and the health student; each person becomes both a student and an educator.

The extent to which communities could “own” their health care is an unexplored idea. Community residents and organizations could contribute to a scholarship fund to help send a local resident for training. The student could be trained as a mid-level practitioner, dentist, hygienist, or general practitioner who would return to the area. Alternatively, communities could hold fundraising drives or seek out donations from health care organizations to obtain equipment that would assist them in self-care (e.g., blood pressure gauges). This equipment could be placed at a community center or church.

**CONCLUSIONS**

We have explored solutions to health care problems based on ethnographic data from a small community. We were interested in contextualized social change that might alleviate suffering and destabilize hegemonic narratives. Even when new solutions are proposed, contradictions are likely to emerge. Yet when the solutions are based on a socio-historical understanding of the various stakeholders, these dangers are decreased. We sought to demonstrate the generative potential of a critical research approach, contribute to moving beyond the impasse between critical and poststructural research agendas, and, hopefully, encourage other scholars to pursue research in the interest of
consumers.
References


Regional Health Planning District Report (cite disguised to protect anonymity of county).


State Primary Care Association (cite disguised to protect anonymity of county).


Appendix A
Overview of Fairmount County Women’s Health Project

A team of university researchers interested in women’s health issues, in partnership with the Fairmount County Women’s Health Collective (FCWHC), began work in early 1993 to “lay[ing] the foundation for a women’s health promotion project to improve the health and quality of life of women living in Fairmount County” (FCWHC Project Grant Proposal, 1993). The first author was a member of the project team. The stated goals of this endeavor were 1) to research the health needs and concerns of women living in Fairmount County, 2) to support and strengthen the fledgling Fairmount County Women’s Health Collective, and 3) to develop a model for the design of community-based women’s health promotion programming in Fairmount County which can be employed in other rural areas (FCWHC Project Grant Proposal, 1993).

This community/university partnership is “grounded in the philosophies of community empowerment, competency building, and reciprocity in research, and in the principles of action research espoused by Lewin (Mittelmark 1990), and those of shared ownership and collaboration which are tenets of feminist scholarship” (FCWHC Project Grant Proposal, 1993).

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\(^1\)Throughout the paper, all individuals, organizations, cities, and counties were given fictitious names to protect the confidentiality of the informants. In some instances, data had to be aggregated to protect the informants’ identity (e.g., the physicians’ descriptions).

\(^2\)Donations were not actively solicited by staff members. Rather, a handwritten sign indicated that donations were gladly accepted. Consumers understood through word-of-mouth that donations helped to keep the Healthmobile running.

\(^3\)This theme of people’s aversion to getting “something for nothing” occurred repeatedly. For example, the Marsh Creek Community Center held periodic clothing sales that were a much needed service. For many community residents, these sales were their only source of clothing. The Marsh Creek volunteers said that when the sales first began, they tried to sell items for $1.00 each, but they learned that price was too high. Then they tried providing the clothes for free, and learned that people were too proud to accept the clothes for free. For the next sale, volunteers set the price at 25 cents per item; this pricing strategy was effective because it was sensitive to the local values.

\(^4\)We do not want to exaggerate the researchers’ role in these activities. The awareness and praxis that arose from this research in large part depended on the efforts of the participants themselves, community members, the Fairmount County Women’s Health Project, and other concerned people.