

**UNEASY TENSIONS IN HEALTH CARE DELIVERY IN A RURAL APPALACHIAN  
COAL MINING COMMUNITY: ENVISIONING ALTERNATIVE SOLUTIONS**

by

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(ABSTRACT)

Research consistently supports that some segments of society are at considerably higher risk for illness and death than the national average. While the existence and extent of poor health outcomes for these "vulnerable populations" are well documented, less research attempts to explain why such inequities persist and how they might be resolved. Thus, many vulnerable individuals fail to get adequate health care.

How can health care delivery be improved to better serve those consumers most at-risk of poor health? Addressing this issue requires an in-depth understanding of the unique health and social needs of vulnerable consumers and how these needs are being met (or not met) by the health care industry. Based on field research using a variety of methods, this study examined health care delivery to one at-risk population, women in a rural Appalachian coal mining community, with the ultimate goal of envisioning service design and distribution strategies that might better serve disadvantaged populations.

Consistent with the change-oriented goal of this research, a feminist approach guided this study. Women's everyday experiences in managing their health needs were explored through an analysis of their health care stories. Health care providers were also interviewed in order to explore both sides of the service encounter dyad. The voices of the women and the providers reveal uneasy tensions in health care delivery and illuminate why the current system does not meet the actual health care needs of the women or their community. A variety of solutions are offered to improve health care delivery.

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## **PART ONE**

### **THE PROBLEM**

Part I, "The Problem," describes the research questions and their importance (Chapter 1), the methodology employed (Chapter 2), and the setting of the study (Chapter 3). Chapter 1 discusses how despite improvements in access to health care over time, many consumers in the United States still fail to receive adequate care. In studying health care delivery to one vulnerable population, this dissertation investigates why these inequities persist and explores ways to improve health care delivery to better serve at-risk consumers. The end of Chapter 1 outlines the organization of the dissertation. Chapter 2 describes the evolving research design. This research incorporated multiple field research methods and was guided by a feminist orientation. Chapter 3 describes the research setting, a rural Appalachian coal mining community, and explores how the sociohistorical context of the community affects health care delivery.

## CHAPTER ONE

### INTRODUCTION

Two out of three women around the world presently suffer from the most debilitating disease known to humanity.... The disease is poverty.... Measured in dollar terms alone, poor people have less income to spend on nutritious food, clean water, and adequate clothing and shelter, assets requisite to a minimum level of health and well-being. Engaged in a daily struggle to meet basic health needs, the poor often can not avail themselves of preventive health care, or save for the exigencies of unexpected illness.... (Jacobson 1993, p. 3).<sup>1</sup>

Women face severe health risks worldwide. Yet within the national boundaries of one of the most economically developed countries in the world, even the United States health care delivery system fails to meet the needs of numerous groups of consumers. During the last four decades, dramatic changes in the financing and delivery of health care in our country have improved access to care for many of the traditionally disadvantaged segments of society. For example, policy developments such as the enactment of Medicaid and Medicare in 1965 put medical care within the reach of many of the nation's poor and elderly. Yet in spite of such improvements in the accessibility of health care, inequities in access to care persist, and, for some populations, barriers to care have increased (Aday 1993; Lillie-Blanton, Martinez, Taylor, and Robinson 1993).

In recent years, for instance, Medicaid benefits in several states have become more restrictive because of cuts in federal financing. Twenty years ago, about sixty percent of the poor were covered by this program, however, only about forty percent currently receive coverage (Aday 1993). The degree of access to hospitals in rural communities is also dropping. Rural hospitals are facing levels of instability not encountered since the Great Depression; many are closing their doors completely and, for others, demand is being pushed beyond capacity (Mick 1990; Straub and Walzer 1992). Similarly, the infant mortality rate among at-risk populations is high; income, race, and ethnicity serve as powerful predictors of infant mortality (Nersesian 1988). Low-income and nonwhite women are at greatest risk for poor birth outcomes, yet they receive the poorest prenatal care (Lia-Hoagberg, Rode, Skovholt, Oberg, Berg, Mullett, and Choi 1990).

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<sup>1</sup>See Hill and Macan (1996) for a discussion of how the plight of people in poverty is expected to worsen.

These examples highlight the fact that, despite improvements in accessibility, the health care needs of numerous segments of society are still not being adequately met by the current health care system. Research consistently finds that certain populations are at considerably higher risk for illness and death than the national average. Examples include rural residents (e.g., Straub and Walzer 1992), the elderly (e.g., Feder 1990; Phillips, Schuler, and Jacobs 1994), African Americans (e.g., Kochanek et al. 1994), and the homeless (Hill 1991), to name a few. The existence and extent of poor health outcomes in "vulnerable populations,"<sup>2</sup> defined as those groups at risk of poor physical, psychological, and/or social health (Aday 1993), are well documented. Less progress exists, however, in explaining *why* such disparities persist (Feinstein 1993). Further, "the solutions to addressing the needs of these diverse groups have been fragmented and categoric--resulting in many particularly at-risk individuals slipping through the cracks of the existing health and social service systems" (Aday 1993, p. xvii).

Why are vulnerable populations slipping through the cracks of the health care system and how can this be prevented? How can health care delivery be improved to better serve those most at-risk of poor health? These are the broad research questions this dissertation sought to address. This research critically investigated health care delivery to one vulnerable population--women in a rural Appalachian coal mining community, Fairmount County (a fictitious name).<sup>3</sup> A host of risk factors exist that make people more or less vulnerable to poor health: demographic characteristics (e.g., race/ethnicity, class, gender, sexual orientation, age, income, education), economic conditions (e.g., unemployment rates), environmental conditions (e.g., air and water quality), community resources (e.g., health and social services, housing), and public policies (e.g., qualification requirements for Medicaid benefits), to name a few. Women in Fairmount County were chosen as the population for investigation since they face multiple environmental, economic, and demographic vulnerabilities to poor health status and access.

The field of services marketing is uniquely poised to contribute to the task of critiquing health care delivery and developing alternatives that might better serve the needs of vulnerable populations. The services marketing literature suggests that services are co-created; that is, services arise in the interaction between the health care provider and the consumer, defined as

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<sup>2</sup>The terms vulnerable and at-risk are used interchangeably.

<sup>3</sup>This study contributes to a growing body of research studying marketing issues that impact vulnerable populations. See, e.g., the special issues of *Journal of Public Policy and Marketing* and *American Behavioral Scientist* (Hill 1995a, 1995b) and a special session at the Marketing and Public Policy conference (Qualls and Alwitt 1996). See also Andreason (1975, 1993) and Alwitt and Donley (1996). For studies of health care issues impacting at-risk consumers, see, e.g., Scammon, Li, and Williams (1995); Franzak, Smith, and Desch (1995); Hill (1991); Hill and Macan (1996); and Koemer (1994).

the service encounter (Czepiel, Solomon, and Surprenant 1985; Lovelock 1988; Shostack 1985; Solomon et al. 1985; Surprenant and Solomon 1987). An adequate analysis of the delivery of health care must include both parties in this exchange (e.g., Bitner, Booms, and Mohr 1994; Bitner, Booms, and Tetreault 1990; Brown and Swartz 1989). Moreover, health care is delivered in a complex organizational and social milieu that can affect the provider-consumer interaction. Thus, an understanding of health care delivery to vulnerable populations requires an examination of consumers, providers, and the broader organizational and social contexts in which medical encounters occur (Hansen and Resick 1990). However, past research in services marketing, as well as other fields studying medical service encounters, gives little attention to these broader contextual influences. For instance, a primary criticism of the interdisciplinary body of research on physician-patient relationships is that most of the work is atheoretical and focuses only on selected, narrow aspects of the exchange "without regard to any overall, integrated picture of how doctor-patient relationships reflect dimensions of the larger sociocultural setting in which medicine is practiced" (Allman, Yoels, and Clair 1993, p. 41).<sup>4</sup>

As such, this dissertation analyzed the experiences of Appalachian women and the health care providers that serve them. Many at-risk consumers manage their health needs in ways that avoid interaction with the formal health care system, so this research investigated the women's everyday experiences both within and outside the formal system. Investigating providers' experiences is equally important since their attitudes and practices, as well as the structures and policies of their organizations, can facilitate or act as barriers to at-risk consumers obtaining adequate care. The social and economic context of Fairmount County and its impact on health care were also explored.

The primary objective of this dissertation was to gain a better understanding of the unique health and social needs of at-risk consumers and how their needs are being met (or not met) by today's health care industry. In contrast to much research that merely documents the presence of factors affecting vulnerable individuals' health status and access, this dissertation took a critical stance. It critiqued existing health care delivery in Fairmount County with the ultimate goal of envisioning service design and distribution strategies that might better serve vulnerable populations.

Consistent with the research goal of change, this study was guided by a feminist research approach, which emphasized change and emancipation. In contrast to traditional research methods that assume a detached, objective researcher, feminist methods advocate

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<sup>4</sup>For reviews of this literature, see Inui and Carter (1985), Pendleton (1983), Roter and Hall (1989), and Waitzkin (1984). Stoeckel (1987) provides a good overview of literature on this topic in the popular press. For critical analyses of physician/consumer interactions, see, e.g., Fisher (1986), Fisher and Todd (1983), Fox (1989), and Todd (1989).

openness, engagement, connection, intimacy, and empathy (Oakley 1981; Riger 1988). While feminist research approaches have been advocated within consumer research (Bristor and Fischer 1993; Hirschman 1993; Stern 1993), few applications exist (for exceptions, see Dobscha 1995; Ozanne and Stern 1993). Some of the elements of this research that make it feminist include the desire to document the women's problems in health care, the focus on health care from the point of view of the women, and the presentation of the data as inescapably linked to social context (e.g., Reinhartz 1992). The fieldwork conducted to document the women's problems in health care included observations, engaged participation, focus groups, and in-depth interviews.

### **Uneasy Tensions in Health Care Delivery: Cultures Colliding**

The voices of the women and the providers revealed uneasy tensions in health care delivery that shed light on why the current system does not meet the health care needs of the women or their community. These tensions can in large part be explained by a collision of two cultures. On one side of the medical service encounter were physicians who were educated, trained, and socialized in a medical culture that emphasizes curing disease through the application of invasive procedures and advanced technology. This curing orientation is institutionalized in the design and delivery of health care in today's society--a bureaucratic, cold, impersonal system that treats patients as objects. While the doctors were often motivated by compassion, the care they provided rarely broke free from the boundaries of the curing approach in which they were trained. On the other side of the encounter were health care consumers who celebrated family and community and valued authentic, caring relationships. A critical analysis of the voices of the health care providers and consumers in this rural Appalachian community suggested that the impersonal delivery of welfare medicine collided with the community for which it was meant. This research examines these contradictions in the system in order to identify and explore possible avenues for change.

### **Organization of the Dissertation**

This dissertation is organized as follows. Part I, "The Problem," details the research questions, method, and setting (Chapters 1, 2, and 3, respectively). Chapter 2 on research methodology details the feminist research approach and the evolving design. Chapter 3 sets the stage for the study by describing the local context in which health care is delivered. The study took place in Fairmount County, a poverty-stricken coal mining community in Central Appalachia. This chapter explores, through the voices of women and providers, how the impoverished living conditions and substandard investments in health care in Fairmount County impacted health care access and delivery. Chapter 3 also puts these struggles into the larger sociohistorical context by discussing the history of struggle in Appalachia. Further, it explores the important role of community in Fairmount County. Community arises in part as people fight and struggle against opposing forces; it also sustains people during these times of struggle.

Part II, "The Service Encounter," explores health care delivery in Fairmount County through the voices of the physicians (Chapter 4) and the voices of the women (Chapter 5). These two chapters illuminate numerous problems in health care delivery in this population and shed light on the first research question--why vulnerable populations are slipping through the cracks of existing health care systems. Chapter 4 suggests that health care delivery in Fairmount County is dominated by the "curing" paradigm of the medical establishment that focuses on disease and isolates the disease from the person and her social context. Further, the specialized, technology-based training physicians received ill prepared them for the realities of practicing in an impoverished community. Chapter 5 illuminates numerous difficulties the women experienced in obtaining health care, both in accessing the system and negotiating the service encounter. The women's encounters with the physicians were predominantly negative and were at times dehumanizing. Many of the women opted out of or minimized their use of the health care system because it did not meet their needs. This chapter also explores the numerous strategies the women adopted, within and outside the health care system, to manage their health needs in light of these difficulties. Chapter 6 summarizes the perceptions of the providers and consumers by organizing the results into a set of contradictions. These uneasy tensions in health care delivery exist at a level higher than just the immediate medical service encounter--problems stem from a collision of two cultures. Health care delivery driven by the curing model violated the women's sense of individual worth, their expectations for egalitarianism, and their desire for authentic, caring relationships. Consistent with the critical nature of this research, increasing awareness of these contradictions can serve to stimulate change.

Part III, "Seeking Solutions," addresses the second research question by exploring potential solutions to improve health care delivery to better serve at-risk populations. Chapter 7 analyzes health care delivery provided by a mobile health service in Fairmount County, the Healthmobile, that was hailed by informants as an example of what is good about health care in the region. The care provided by the Healthmobile is very different from conventional health care delivery, and resolves many of the contradictions discussed in Chapter 6. Exploring good examples of health care delivery is an important part of seeking solutions to improve health care delivery for vulnerable populations. Chapter 8 includes recommendations for health care delivery to at-risk populations as well as contributions, limitations, and directions for future research.

## **CHAPTER TWO**

### **METHODOLOGY**

#### **Research Approach and Overview of Methodology**

This study was motivated by my commitment to research that has the potential for social change. Specifically, I wanted to gain a deep understanding of the health and social needs of Fairmount County women and how their needs are being met (or not met) by the existing health care system. Through a critical analysis of the women's experiences with the health care system, perceptions of local health care providers, and the broader organizational and social contexts in which health care delivery occurs, I sought to understand the problems and opportunities in health care delivery to these women. This critique led to identification of potential areas of change to improve service design and delivery to vulnerable populations.

While a variety of research approaches can be used to foster change, I was guided by a feminist approach. Aspects of a feminist approach that were particularly relevant for this study included placing women at the center of the analysis, valuing and giving voice to their everyday experiences and concerns, and seeking social change that would benefit women as well as other subordinated groups (e.g., Fonow and Cook 1991).

The specific methodological approach was feminist-guided fieldwork involving prolonged engagement and immersion in the field, multiple methods and data sources, and an evolving research design. Specific data collection techniques included engaged observation (Belk 1991; Hammersley and Atkinson 1995; Hirschman 1986; Reinharz 1992; Thomas 1993), in-depth interviews (McCracken 1988; Oakley 1981; Reinharz 1992), and focus group interviews (Krueger 1988; Morgan 1993; Morgan and Krueger 1993).

A feminist research approach was appropriate given the nature of the research question and the community studied. First, health care is a complex topic involving intimate issues and sometimes provokes fear and anxiety. Traditional survey methods may be limited in their ability to explore such sensitive issues (e.g., understanding how a woman experiences a pelvic exam). Second, Fairmount County is characterized by low educational levels and many residents are illiterate, rendering methods such as surveys problematic. Additionally, Appalachian people are often skeptical of outsiders (Seitz 1995); both because the region has a history of exploitation and because the people often feel over researched (Fieldnotes 1/14/94). Gaining access to Fairmount County to explore this sensitive and complex issue was facilitated by the feminist approach of this research (i.e., this approach advocates trusting relationships, openness, engagement, and empathy).

## **Chapter Overview**

This chapter is organized as follows. First, I describe the research setting and sample. (More detail on the setting is included in Chapter 3). Second, I outline the research design and data collection techniques, which generally proceeded in two phases: entry into the field and the broad exploration of community health issues, and deep immersion. Data for the first phase included focus group interviews with Fairmount County women, interviews with health and social service providers and community leaders, and fieldnotes from engaged observation at academic, community, and regional Appalachian events and activities. This phase took place over the course of two years and provided me with an understanding of the local health issues and the environmental and economic conditions of Fairmount County, access to informants, and an opportunity to begin building relationships with informants.

During the second phase, deep immersion, I lived in the community and volunteered on the Healthmobile, a mobile health unit serving the area. Data collection included engaged observation of the Healthmobile and daily community life, as well as in-depth interviews with community women. These data were then analyzed. During analysis, I continued regular phone contact with key informants to clarify particular issues and explore emergent themes. Later, I conducted additional in-depth interviews with physicians and new women to challenge these emergent themes.

Finally in this chapter, I review the data analysis process I employed. The remainder of the chapter discusses each part of the methodology in greater detail.

## **Research Setting**

Fairmount County, a rural Appalachian coal mining community, was chosen as the research setting for this dissertation based on the primary criterion of "multiple vulnerabilities." That is, the community has multiple risks that make its residents vulnerable to poor health. Examining the experiences of people most at-risk for poor health should help reveal the broadest range of circumstances in which the health care industry fails to meet the needs of vulnerable consumers. These health risks are many and include rural isolation, adverse economic conditions, and environmental and occupational hazards. Risks also stem from the community's designation as a medically underserved community and a health professional shortage area.<sup>5</sup>

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<sup>5</sup>These risks are detailed in Chapter 3 which examines the social and economic context of this study. The risk of gender is explored in the current chapter to motivate the choice of women for analysis.

Another factor in the selection of this site was that I was already involved in a related research project. That is, I initially became involved in Fairmount County health issues through participation in a university women's research team<sup>6</sup> working in collaboration with the Fairmount County Women's Health Collective<sup>7</sup> on a rural women's health project in the county (hereafter referred to as the Fairmount County Women's Health (FCWH) project--a description of this project and its feminist ideals is provided in Appendix A.) This involvement motivated my interest in doing a more in-depth exploration of health care delivery in this community for my dissertation. Further, I had access to the project's existing data on health needs and concerns in the community. Thus, both my involvement on the research team and this existing data offered entry points for this dissertation.

### **Sample**

As noted earlier, because the service encounter is co-created by both the consumer and the provider, an adequate analysis of the delivery of health care should explore the service encounter *dyad*.

### **Women**

Appalachian women are a relevant population for investigation because women traditionally serve as the primary caretakers for their families and are thus the primary health care consumers and decision-makers. Further, in addition to the risks of poor health discussed above, Fairmount County women face the additional risk of gender. Gender is a risk because women have traditionally been subordinated on the basis of their gender. Appalachian women are especially impacted by the social construction of gender in that they are socialized into family roles where they are expected "to meet the needs and wishes of parents, husbands, and children" (Fiene 1993, p. 42). Further, the combination of disadvantages facing poor and minority women (e.g., class, culture, race/ethnicity) increase

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<sup>6</sup>This team does not have a formal name. I will refer to it as the rural women's health research team. The team is interdisciplinary and composed of faculty, staff, and graduate students.

<sup>7</sup>The Fairmount County Women's Health Collective is an informal group of community women concerned about health care issues of women in the county. The Collective formed in 1992 out of concern that preventive health care services, specifically pap smears and mammograms, were not being well utilized by area women. The group is currently comprised of nurses, social workers, physicians, and a health educator. To date, their primary activities have been conducting a needs assessment of women's health needs with the assistance of the university researchers, and co-sponsoring health fairs.

the likelihood that they will have serious health needs and that those needs will not be adequately met (Zambrana 1987).

Women sampled in this study included participants in focus groups and in-depth interviews, and those studied during engaged observation on the Healthmobile and in the community. First, forty-four women from the community, ranging in age from 20 to over 70, were involved in six focus group interviews for the Fairmount County Women's Health project. Table 1 lists the groups of women that participated. Purposeful sampling was used to select these groups. Cancer patients were chosen because they have lots of contact with the health care system. Other groups were chosen to represent different risks of poor health (e.g., low income, African American, senior citizens).

Second, eleven women participated in the interview portion of my research (see Table 2 for their profiles and a list of their pseudonyms). A dimensional sampling strategy was used (Arnold 1970; Johnson 1990). That is, I determined three dimensions on which variability was desired and then searched for representative informants for each dimension. These dimensions were the nature of health problems (i.e., few/many, chronic/acute), the extent of contact with the formal health care system (i.e., high/low), and resource availability (i.e., income, insurance, and transportation).

Finally, during my engaged observation on the Healthmobile and in the community, I observed and spoke with literally dozens of women throughout the county.

## **Providers**

Two sets of providers were examined. First, health care providers (physicians, nurses, and administrators), social service providers, and community leaders were interviewed as part of the Fairmount County Women's Health project. Table 3 lists these participants. Second, I recruited additional physicians for in-depth interviews. Since the physician-client relationship is at the heart of the service encounter, it was important to have more data from the physicians. Doctors were sampled based on availability and consent. Out of the six primary care physicians in the county, four agreed to be interviewed. Additionally, since some Fairmount County consumers (and poor consumers in general) contact the emergency room for primary care, I solicited an interview with an ER physician at the county hospital. Third, I interviewed the director of a mobile health unit, the Healthmobile. See Table 4 for the profiles and pseudonyms of the six providers that I interviewed.

For my primary data collection with both the women and providers, the sampling strategy was based on redundancy. In other words, additional informants were sampled until insights from the data started exhibiting diminishing returns (McCracken 1988).

In the next section, the emergent design for this dissertation is broadly outlined.

## **Evolving Research Design and Data Collection Techniques**

In general, this research proceeded in two phases: entry into the field and the broad exploration of community health issues, and deep immersion.<sup>8</sup> This section describes data collection activities within each phase. (See Table 5 for a summary of the evolving research design and data collection activities).

### **Field Entry and Exploration of Broad Community Health Issues**

Participation in the Fairmount County Women's Health project, analysis of the existing project data and other secondary data, and attendance at various Appalachian events and activities were the primary activities that facilitated the first phase of my research. During this phase, I gained a broad understanding of health care delivery and major health issues in Fairmount County (including key organizations and providers), an understanding of the social context of the study (including economic and environmental conditions, language, culture, values, norms), initial access to informants, and an opportunity to begin building relationships with informants.

*Fairmount County Women's Health (FCWH) Project.* Analysis of existing data from the FCWH project served as the primary entry point for this study. The data consisted of six focus group interviews with area women and twenty-two semi-structured interviews with health care providers, social service workers, and community leaders, all conducted in the Fall of 1993. Tables 1 and 3 list the focus group and individual interview participants. Members of the university rural women's health research team served as interviewers and as focus group facilitators and recorders. All individual and focus group interviews were tape recorded. All of the focus group data and those key informant interviews most relevant to my dissertation were transcribed.<sup>9</sup>

As illustrated in Table 6, the questions that were discussed in the focus groups explored broad issues of health care in the community. The provider interview data from the FCWH project also were useful in providing general background information and insight into provider perspectives on community health care issues (see Table 7 for a list of interview

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<sup>8</sup>These phases are used merely to facilitate exposition since the process of field research is not actually done in a series of stages or steps. Rather, the processes are "overlapping, ongoing, reciprocal, and embedded" as well as "synergistic" (Bailey 1996, p. xiv). Thus, division of the design into these two phases is done purely for rhetorical purposes.

<sup>9</sup>The expense of transcribing all of the provider interviews from the Fairmount County Women's Health project was not justified. All interviews with health care providers and some with social service providers were transcribed. For the remaining interviews, I constructed detailed notes from the tapes and reported any relevant direct quotations.

questions). Since a key objective in the early stage of the FCWH project was to do a health care needs assessment in the county, these interviews focused more on identifying the community's health care concerns. Therefore, primary data collection with more providers and women during the deep immersion phase (discussed below) were needed to supplement these interviews and specifically explore *service delivery* issues.<sup>10</sup>

*Other Secondary Data.* Two other sets of data, on area health organizations/services and the census, were also analyzed. First, information on the range of health services available in Fairmount County, the health and social service organizations/providers serving the county, and community health status data were obtained from local contact people and sources such as the regional health district, county Extension office, and Chamber of Commerce. Second, census data (e.g., population, employment, occupation, income, education, and morbidity statistics) were analyzed in order to more fully understand the social, cultural, and economic situation of the area.

*Appalachian Activities.* Other activities that helped enhance the entry and broad exploration phase of my research included preparing and presenting some of the FCWH project data at the Appalachian Studies Association conferences, participating in a biannual "In Praise of Mountain Women" gathering, attending meetings of a local cancer survivors' support group and the county steering committee for the Central Highlands Appalachian Leadership Initiative on Cancer, attending a national Violence Against Women rally as part of the delegation from the Appalachian Women's Alliance, and serving as a sister (members are called sisters) of this organization.

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<sup>10</sup>My analysis of the project data was independent. That is, project team members (from both the university research team and the Fairmount County Women's Health Collective) did a quick analysis of the data in order to share preliminary results with county residents, community leaders, and academic colleagues. However, this rich data source was never thoroughly and rigorously analyzed by the project members. A notable exception is a master's thesis by one of the team members. This thesis is not cited to maintain confidentiality of the community.

One very action-oriented and empowering result of these preliminary analyses by project participants was the development of a readers' theater script to spread the word about Appalachian women's health care issues. The Fairmount County Women's Health Collective decided to write vignettes based on the data and share them with community residents and leaders as a way to raise consciousness about women's health issues. A university team member wrote the script, and the Collective scheduled multiple performances throughout the Appalachian region. I was involved once as one of the readers and often provided transportation for the community women to get to the performances. These experiences further enriched my understanding of the women's health care needs.

## Deep Immersion

Three central findings that emerged from my analysis of data from the first phase of this research guided data collection during the deep immersion phase. (These findings are discussed at length in Chapters 4 through 6). First, an interesting contradiction emerged between the perspectives of the women and the providers/community leaders. The providers/leaders largely attributed women's poor health status and access to a lack of education (e.g., lack of knowledge about available health and social services and about the relationship between individual behavior and health outcomes). Not surprisingly in light of this perspective, the providers/leaders believed that education should be the primary solution for improving women's health. Contrary to these opinions, the women were very knowledgeable about health issues. They attributed poor health status and access to issues such as economic conditions, environmental hazards, and lack of needed providers and services, and their proposed solutions to improve health outcomes focused on addressing such structural issues.

Second, the women reported extremely negative experiences with the formal health care system, including barriers to access, stereotyping of poor people, and, in general, a system that did not meet their needs. The service encounter in particular was described as an intimidating, alienating, often dehumanizing experience. Doctors were described as cold, distant, and insensitive. Many women left the formal health care system because of these experiences and the system's failure to meet their needs.

Third, one example of *good* health care delivery emerged. The Healthmobile was identified as a location where health care was provided in a caring, sensitive manner.

Based on these initial emergent themes, additional data were collected. I wanted to investigate more fully the nature of the women's experiences in the service encounter. Why were the service encounters so dehumanizing? Why were women's and providers' viewpoints so at odds? Further, I wanted to explore the nature of health care delivery on the Healthmobile in order to understand what made for good health care delivery and to compare and contrast the different types of experiences the women encountered in the formal versus informal health care delivery systems. I went to the field to explore these issues. Fieldwork included living in the community, volunteering on the Healthmobile, and conducting in-depth interviews with women and providers.<sup>11</sup>

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<sup>11</sup>I use the terms fieldwork and field research interchangeably like many researchers. However, I want to highlight Bailey's (1996) distinction between the terms to stress that while my fieldwork (actual time immersed in the research setting) was time bound, my field research spanned the entire course of the project. For instance, field research began when I entered the field initially through involvement in the women's health project. Similarly, while analyzing data, one is still engaged in field research. The entire research process spanned three years.

During fieldwork, I was able to both challenge and refine emerging themes and identify new ones. During this phase of the research, I also developed intimate relationships with many of my informants. This experience in the field helped me to understand the women's health care experiences in even greater depth. This section begins by describing the Healthmobile and my activities as a volunteer. Then I describe my living arrangements and community activities. Next, I describe my relationship with participants in the study and how this relationship influenced the quality of my data. I also discuss the numerous ways that a key informant aided my study. Finally, my primary data collection activities during fieldwork--engaged observation, informal interviews, and in-depth interviews--are reviewed.

*Volunteering on the Healthmobile.* I was immersed in the field for six weeks when I lived in the community and volunteered on the Healthmobile (HM), a mobile health service serving Fairmount County and a neighboring county. The HM visits two locations on a weekly basis and four on a biweekly basis. Most clients are from the two county area, but some travel as far as 60 miles from neighboring counties and states. 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 who is currently pursuing a nursing degree.<sup>12</sup> All three women live in the local area--Andrea and Christina are natives of the region and Sister Kay has lived in the community for over 18 years. The HM is sponsored by a Catholic hospital in a neighboring county.

The Healthmobile's main services are preventive and primary care, provision of medication, provider and resource referrals, and counseling. Appendix B provides a more detailed and comprehensive description of the services provided. All services and medications are offered free of charge. The HM service is funded primarily through grants, which are supplemented by the sponsoring hospital and donations. Local physicians donate surplus drug samples, and clients make voluntary donations to help purchase gasoline and medicines.

The Healthmobile is a 28-foot Winnebago outfitted as a clinic. It includes a primary service area, private exam room, and storage area for supplies, medicines, and client records. The vehicle is over eight years old. It is in need of multiple mechanical repairs, the interior is worn, and space is inadequate.

Only some of the clients go to the private exam room. Therefore much of the care provided is done in a group setting. About five to six clients can sit at once in the primary service area, so health care is generally provided with other clients present.

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<sup>12</sup>All names are pseudonyms. Throughout the dissertation, names of informants, organizations, and locations are disguised.

I had a variety of roles as a volunteer on the Healthmobile. My activities included greeting and talking with clients,<sup>13</sup> accepting and storing donations, and getting clients to sign in (or helping them if they needed help writing). Occasionally the staff asked me to help conduct an introductory interview with a new client and complete a client information form. I also helped administer a survey of client evaluations of the HM. For some clients I just told them about the survey and its goal to improve the HM services and gave them the survey form and a pencil. For clients who could not read or write, we completed the survey together and I wrote the comments down.

The remainder of my activities were to assist the staff after regular hours. These activities included helping prepare client applications for indigent patient assistance programs,<sup>14</sup> and helping to prepare grant applications to get a new vehicle, renew staff members' contracts, and expand existing services.

*Living in the Community.* I lived at the Marsh Creek Community Center (MCCC) during my fieldwork. The MCCC is a community-based organization with a long history of serving the needs of low income people and the community. Activities and services of the center include SHARE (Self-Help and Resource Exchange, a program providing food monthly at low cost), adult basic education and general equivalency degree classes, organized play and story telling for pre-school children, vacation bible school for children and teens, Appalachian experiences for college and church groups, dances and community celebrations, workshops and leadership training sessions, and forums on current issues. The center is run by volunteers.

The conditions of the center were very primitive. I originally chose to stay at the MCCC to save money (\$7 per night), but living at the community center had additional benefits. I had an opportunity to learn about the community and meet women. Further, the women were impressed that I did not consider myself "too good" to stay there. I helped out and volunteered at the center as needed.

*Relationship Management.* The quality of the data generated in feminist field research in large part depends on the quality of the relationship between the researcher and the participants. Thus, "managing" the research relationship is very important. For instance, how does the researcher enter the site of the fieldwork? In this study, I could have stressed my role as an academic researcher. In this role I might have highlighted my knowledge,

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<sup>13</sup>Talking with clients was an integral part of health care delivery on the HM. Staff members and clients talked about everything, ranging from "how is your garden" and "how are your grandchildren" to "what brings you in today?" and "how did that medicine work out?"

<sup>14</sup>These are programs sponsored by pharmaceutical companies that supply free medications for consumers who qualify.

experience, and university affiliation. However, this role of researcher would have amplified my power in the research relationship (Reinharz 1992). Instead, consistent with feminist research, I sought to reduce power differences in the relationship. For example, I dressed casually, avoided the use of academic jargon, and lived in the impoverished conditions at the community center.

During fieldwork, I introduced myself (or was introduced) as a student and/or a Healthmobile volunteer. For example, upon conducting formal in-depth interviews, I told the women that I was a student who wanted to listen to and learn from them. I asked them to share their health care stories, both good and bad, in order to help me better understand what it is like to be a woman in Fairmount County trying to get her health needs met. Before long, some people were referring to me as "that woman who wants to know our health care stories." Thus, I chose to amplify my very real dependence on the women for gaining insight into their struggles. Further, my ethical stance necessitated this open communication of my research role and purpose.

As a Healthmobile volunteer, my role had additional dimensions. The HM staff members introduced me in the beginning as a volunteer, student, friend, or some combination of these labels. The majority of clients accepted me immediately as part of the HM "team." Within only a week, regular clients were hugging me upon entering and leaving the HM just like they did the other staff members. A few weeks into field research, the HM director said "I forget to introduce you now because we all see you as so much a part of our team." This "insider" status was particularly valuable given that research suggests that Appalachian people are sometimes skeptical of outsiders (Seitz 1995). In talking with the women casually and doing informal interviews on the HM, I reiterated that I was a student and used a similar approach to the one used in interviews (i.e., that I was interested in listening to and learning from them about their health care experiences). Another dimension of my role was as an advocate. The women viewed me as a community friend and advocate since I was doing this research with the goal of improving health care delivery in Fairmount County.

*Key Informant.* The Healthmobile director, Sister Kay, was my key informant for this research. She facilitated my entry into the field in five ways. First, she allowed me to conduct my research on the Healthmobile. Second, she communicated my role on the HM to clients by introducing me as a friend of the HM or just as a friend in general. Third, given Sister Kay's role of respected friend and advocate for the community, my introduction had credibility. Fourth, she was an invaluable resource for information on clients, health care in the community, and historical information on the community. Fifth, she introduced me to non-Healthmobile clients who she suggested would be valuable informants based on my sampling criteria.

*Data Collection Activities.* Data collection activities included engaged observation, informal interviews, and in-depth interviews.

*Engaged Observation and Informal Interviews.* I blended in easily in my role as a Healthmobile volunteer, in large part because I was associated with the staff and viewed as part of their team. I worked every day the HM operated (four days per week for four to five hours per day). While working as a volunteer, I observed firsthand the operations of the HM and the interactions between and among staff and clients. I saw what made health care delivery on the HM different from conventional health care delivery. After about a month, I had started developing relationships with some of the women and began to engage them in informal interviews. I asked them about their health care stories, but the talks were informant-directed. These talks lasted from about ten to thirty minutes, depending on the women's time constraints and how busy the HM was at the time. Some of these informal interviews were private, others were done in a group setting with the staff and other clients participating. Because talking played such a central role on the HM, my request for stories was a natural extension of this form of conversation. In other words, asking the women about their stories blended in with the atmosphere of the HM.

I also had daily conversations with the staff members. Driving to and from locations was both fun and informative. It gave me lots of time to observe how they interacted; get to know them on a personal level; learn more about the HM services, mission, and clients; and learn about their views on community health issues. I also did engaged observation and informal interviews at the Marsh Creek Community Center. I would stop by every afternoon after the day on the HM and just hang out with the volunteers and any people who were there for activities or services. My interactions with several informants, particularly HM staff and regular clients and MCCC key volunteers, developed into friendship.

Engaged observation and informal interviews on the HM and at the MCCC gave me lots of insight into the women's daily lives and management of their health. After about a month, I started approaching women for formal interviews. I conducted five in-depth interviews during my last week of working on the Healthmobile to explore in more depth what I had learned from my data analysis to date. Six additional interviews with different women were done about eight months after I had exited the field, done more data analysis, and needed to challenge and refine themes. Six formal provider interviews were done at that time as well.

*In-Depth Interviews with Women.* Eleven in-depth interviews were conducted with women, ranging in length from 40 minutes to three hours (see profiles of the women in Table 2). Six interviews were conducted in the women's homes. Five informants selected alternative interview locations based on individual needs (see Table 2 for a list of these alternative sites).

I opened interviews by introducing myself, my role, and my background (including my participation in the Fairmount County Women's Health project); discussing the purpose of the study and how the data would be used; assuring confidentiality; and gaining consent (see Appendix C for my Informed Consent Form which was approved by the university

Institutional Review Board). I also asked the women about the type and frequency of their contact with the health care system to gauge usage levels. Consistent with feminist practice, I let the women's stories guide the interview (Reinharz 1992). That is, I asked informants to tell me both good and bad health care stories. From that point, interviews were driven primarily by the informants' interests. In the context of their stories, I probed on other domains of interest (see Table 8 for a list of domains). By encouraging the interviewee to guide the discussion, I focused less on my predetermined areas of interest and more on the experiences of each woman. Some key advantages of this approach are that it reduces the power differential between researcher and informant, allows informants to discuss those issues most important to them, and enables researchers to discover more subtle issues that might not be uncovered through a fixed set of questions.

Recall that feminist research methods advocate openness, engagement, connection, intimacy, and empathy (Oakley 1981; Riger 1988). Feminist methodology values informants as individuals, not just as sources of data. Another way that I incorporated feminist interviewing principles was by enabling participants to express thoughts in their own words and on their own terms. This technique avoids the tendency to label an interviewee's thoughts in the researcher's terms. It also means being flexible when informants digress from topics of primary interest to the researcher to topics of primary interest to the women. Encouraging such "digressions" can not only help make informants feel more comfortable but can also provide a richer source of data.

Finally, developing trust and rapport was crucial. Feminist researchers have suggested numerous practical techniques to achieve these goals such as downplaying one's professional status; recall that I did this through my positioning as a student/listener/learner rather than as a researcher (Reinharz 1992). Self-disclosure also contributes to trust building. Such disclosure can help put participants at ease and reduce the power differential between researcher and informant. It also contributes to "true dialogue" by enabling informants to become "co-researchers" (Bristow and Esper 1988). In my research, the most common questions informants asked me about were my own health care experiences, how I would use this research, and how this research could help the community. These are but a few of the numerous practices used by feminist researchers. Readers are directed to Fonow and Cook (1991), Nielsen (1990), and Reinharz (1992) for more extensive discussions of feminist interviewing.

Numerous signals, particularly non-verbal signals, indicated that the interviewees were comfortable with me and with sharing their stories.<sup>15</sup> They were excited and flattered by my interest in them and their experiences and were very willing to talk with me. Some women showed me around and/or helped me get oriented to the community. Some included me in daily activities (e.g., church, meals, errands). Other indications of the participants' comfort were that they revealed intimate issues and referred me to other informants. The family feeling, frankness, and openness of our talking also facilitated these interviews.<sup>16</sup>

*In-Depth Interviews with Providers.* Six in-depth interviews were conducted with health care providers. Four were physicians in private practice, one was an emergency room physician, and one was a certified family nurse practitioner, the director of the Healthmobile (see Table 4 for their profiles). These interviews ranged in length from 40 minutes to two hours. I opened the interviews by introducing myself as a student and explaining the purpose of my research, assuring confidentiality, and gaining consent. I again positioned myself as a listener and learner, and this facilitated dialogue. Like the women's interviews, I let the providers' stories drive the interviews. I asked broad "grand tour" questions to introduce my domains of interest (see Table 9), and probed within each of those domains (McCracken 1988).

*Ethical Considerations.* Ethical considerations are an important part of field research, particularly issues of deception and confidentiality. I openly communicated my research role to all informants and ensured confidentiality in multiple ways. These methods included

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<sup>15</sup>One signal that was somewhat surprising to me was the presence of husbands at two interviews. I originally thought this might hinder the interviews, but was wrong. Anita brought her husband because they are "soulmates" and like to do everything together. She also wanted his emotional support because she was sharing extremely sensitive health care stories with me. They held hands throughout most of the interview. Helen's husband walked in and out of our interview multiple times just to visit. Helen and I laughed together about how he just liked to "run his mouth" and liked the attention! (I had become really close to Helen and her husband by the time this interview took place, so we were really comfortable joking with one another.)

<sup>16</sup>While most of my interactions with informants were smooth, there were exceptions. For example, I mistakenly took the rapport and trust I developed with the majority of the women for granted in one interview. This informant expressed concern about the potential of anything she said about area doctors to cause harm to them. I reiterated the purpose of my research and that all names would be changed. However, this informant continued to be skeptical and I had difficulty gaining her trust. As a result, she was not forthcoming with information and the interview was strained. I learned a valuable lesson: trust must be *earned*; it can never be assumed. (Fieldnotes 3/15/96)

changing all names of people, organizations, and locations;<sup>17</sup> providing summary (versus individual) descriptions of informants; and downplaying or not reporting illegal or unethical behaviors that might potentially cause harm to informants. At all times I applied the ethical principle of doing no harm to informants, relationships with informants, the research setting, or myself (Bailey 1996). Other aspects of my ethical stance were my reciprocal role and my advocacy role. That is, I sought to give something back to the women and the community. My personal ethical position and feminism did not allow me to just collect data from the community and do nothing in return. Some of the ways I gave back to the community were by listening to the women and their stories, preserving the women's voices, serving as a Healthmobile volunteer, developing potential solutions to improve health care delivery in the county, and continuing to serve as a friend to the women and community and as an advocate for their health issues and concerns.

*Exiting the Field.* Ending the most intense portion of my fieldwork (i.e., the six weeks volunteering on the Healthmobile) was determined by both data redundancy and practicality. By the end of this period, I was generating fewer insights from this deep immersion and active participation phase of my fieldwork. Time, energy, and monetary constraints were also factors.

However, consistent with feminist research, my exiting the field was not clear cut. Rather, I continued my relationships with informants, albeit in a different, long distance manner. An important principle of feminist research is giving primacy to relationships. Many of my relationships with informants have evolved into friendship. Further, my personal ethical stance required this continued involvement. I am committed to the women and Fairmount County.

I have continued these relationships in numerous ways. I maintained phone contact with informants throughout analysis and writing in order to discuss and challenge themes and to maintain their involvement in and contribution to the research. I hosted a get together shortly after my dissertation defense in order to show appreciation to all who participated in my study. I am currently in the process of discussing my key findings and recommendations with informants and getting their input on my future research and writing. We are brainstorming together about ways to disseminate the research results in local venues (e.g., county newspaper, Appalachian publications) and about how results and recommendations might be best used and put into action to benefit Fairmount County. I will continue to seek their input and participation in my research since my dissertation is merely the starting point for my research stream and is only the beginning of my commitment to and involvement in Fairmount County. Further, I continue to be a volunteer, friend, and advocate for the Healthmobile by serving as a sounding board for staff members to discuss ideas and concerns,

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<sup>17</sup>I even disguised some citations to protect the confidentiality of the county.

and by continuing to help with grant writing. I anticipate that I will continue this involvement for many years to come.

## **Data Analysis**

*Managing and Recording Data.* Interview and focus group data included cassette tapes and transcripts. I used fieldnotes (e.g., Sanjek 1990) as the primary method of recording engaged observation. While in the field, I kept a notebook to record events. Immediately upon returning home, I typed fieldnotes using the temporal list of events in the notebook to guide my notes.

*Data Analysis.* I used a hermeneutical approach to analyze the data (e.g., McCracken 1988; Spradley 1979). This is an iterative approach in which analytical categories evolve and expand as the data are iteratively analyzed. Key components of this approach are that it is data driven, requires that the researcher move back and forth between the text and the literature, and involves multiple iterations of looking for themes and patterns within and across informants. That is, I conducted a deep within-subject analysis to help identify central themes, and then looked for patterns across subjects. Several iterations were needed to challenge, expand, and refine the evolving themes and to form them into a coherent and consistent interpretation. Writing and data analysis were intimately intertwined; writing was part of the analysis.

Some people think that qualitative research merely *presents* the words of informants and accepts their perceptions of reality.<sup>18</sup> This is not the case. Qualitative research involves an *analysis* of informants' words. While I did put informants' voices at the center of my analysis, this does not mean I studied their voices uncritically. Rather, through my analysis, I added my voice to their voices. I listened to and preserved their voices, but my analysis did not end there. Through a deep understanding of the very real concerns of the women and the providers within the social context of health care delivery Fairmount County, I developed an interpretation that went beyond the immediate voices of informants to generate new insights.

Given the active role of the researcher in shaping the analysis, it is important to consider how who we are impacts the research process. Research and writing are situationally

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<sup>18</sup>Believing informants is a key principle in feminist research, in contrast to positivistic methods that maintain a skeptical stance. Further, while positivists assume a real and objective reality that exists independently of individuals' perceptions, interpretivists view reality as socially constructed. That is, there is no objective reality independent of the social meaning people give to it (Hudson and Ozanne 1988). Informants' perceptions of health care are their reality and it is these perceptions that impact their attitudes and behaviors (e.g., service quality perceptions, satisfaction, likelihood of exit, repeat patronage).

specific; affected by our background, status characteristics, and personalities; and affected by relationships developed in the field (Bailey 1996; Warren 1988). Rosaldo (1993) uses the concept of the "positioned subject" to help describe how the position of the researcher impacts the knowledge and insight she is able to glean from observing other cultures.

The ethnographer, as a positioned subject, grasps certain human phenomena better than others. He or she occupies a position or structural location and observes with a particular angle of vision. Consider, for example, how age, gender, being an outsider, and association with a neocolonial regime influence what the ethnographer learns. The notion of position also refers to how life experiences both enable and inhibit particular kinds of insight (Rosaldo 1993, p. 19).

He goes further to discuss how "natives are also positioned subjects who have a distinctive mix of insight and blindness" (Rosaldo 1993, p. 19) and how their structural positions, too, impact the relationship between researcher and informant and influence what information is divulged. For this reason, researchers must continually reposition themselves throughout the process of coming to understand a culture. This concept of positioning is extremely useful in reminding researchers to be continually cognizant of how their own and their informants' positions affect data collection and, ultimately, knowledge production.

My research was affected by my status as a white, middle class, 30-year old, educated woman; my Louisiana heritage; my feminism; and my critical and social change orientation. These characteristics affected my choice of research questions, position in the field, entry and exit into the field, rapport and relationships with informants, interviewing style, and analysis and writing. For example, my critical/feminist/social change stance motivated my choice of research questions and methods, and the lens through which I analyzed data; my role as a student and friend of the community facilitated my entry into the field; and my feminist orientation and open personality facilitated my rapport and relationships with informants. My Louisiana heritage was an asset. Some of the older women viewed and treated me as a daughter. My Southern accent facilitated conversation, and the women appreciated that I could understand, at least in part, what it was like to be treated differently based merely on origin (that is, some people perceive Louisianians as backwards, and I have experienced and could relate to such stereotyping and differential treatment). Being middle class and having always lived in cities meant that I had extra work to do to deeply understand what it is like to be poor and live in a rural, impoverished community.

## **CHAPTER THREE**

### **THE SOCIAL AND ECONOMIC CONTEXT OF THE STUDY**

This chapter describes the social and economic context of the study. The study took place in Fairmount County, a poverty-stricken coal mining community in Central Appalachia.<sup>19</sup> As noted earlier, this site was chosen based on the criterion of multiple vulnerabilities (i.e., Fairmount County residents face numerous risk factors that make them vulnerable to poor health).

First, some of the relevant historical and enduring struggles facing Appalachian people are briefly explored. These obstacles include pervasive stereotypes that contribute to attributions of Appalachian people as responsible for their continued poverty, long-term and ongoing battles with the coal industry, and the persistent problem of substandard human services. Second, drawing on the voices of informants, I explore some of the widespread risks of poor health in Fairmount County, including impoverished living conditions and substandard investments in health care, and how they impact health care access and delivery. This discussion addresses local community health risks as well as institutional barriers to health care delivery. Third, the important role of community in Fairmount County is explored. Community is an important concept for understanding Appalachia because people join together to fight against common threats. The bonds of community also help sustain people during times of struggle.

#### **Historical and Enduring Struggles in Appalachia**

Stereotypes of Appalachian people are an enduring problem in our society (Speer 1993). For many Americans, the mention of Appalachia conjures up hillbilly images such as L'il Abner and Daisy Mae, the Beverly Hillbillies, or Hee Haw personalities. Mountain people are described using terms such as ignorant, plain, simple, strong, traditional, and individualistic; they are often described as clannish and labeled as religious fundamentalists. Even seemingly positive terms such as strong, individualistic, and traditional are typically used in a pejorative sense. For example, a strong individualist may ignore the public good; a person who values tradition may resist progress (Fisher 1976).

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<sup>19</sup>Figure 1 represents the Appalachian region as defined by the Appalachian Regional Commission. Various definitions have been proposed based on geography and economic need, and controversy surrounds the issue of defining the region (see Couto (1994) and Ergood (1991) for discussions). Central Appalachia, where this study takes place, is the subregion common to most definitions. It consistently has the highest poverty rates.

These stereotypes contribute to the pervasive representation of Appalachian people as victims of their own cultural inadequacy--as people that possess a defective folk subculture that is responsible for their continued impoverishment (e.g., Weller 1969). From this "culture of poverty"<sup>20</sup> perspective, individual deficiencies are viewed as the root causes of poverty in Appalachia. This view suggests that people are and remain poor because they reproduce and transmit to future generations attitudes and behaviors that inhibit their assimilation into the modern world (Ball 1968; Caudill 1962; Ford 1967; Weller 1969, 1978).

Thus mountain isolation, which began as physical isolation enforced by rugged typography, became mental and cultural isolation, holding people in disadvantaged areas, resisting those changes that would bring them into contact with the outside world. The effect of conditions thus becomes a new cause of conditions, but the cause is now an attitude, not a mountain (Rupert Vance's introduction in Weller 1969, p. vii).

Contemporary researchers of Appalachia have vigorously criticized these culture of poverty explanations. First, the view that Appalachia is a homogenous region and its people have a uniform culture is clearly a myth (Shapiro 1978).<sup>21</sup> Second, this explanation of poverty in Appalachia judges personal traits such as traditionalism as desirable or undesirable based on white, middle-class values without consideration of the perspective of the Appalachian communities (see Lewis 1970). Finally, structural explanations of poverty are ignored. Numerous researchers suggest that the area's poverty can be better explained by forces such as economic exploitation, political domination, and absentee ownership of land and resources rather than by geographic isolation and individual traits.<sup>22</sup> For instance, Couto (1994) implicates the role of business in the impoverishment of Appalachia. He suggests that the economic relations of the region have led "to a transitive verb form, 'to Appalachianize,' which means to develop industry or extract natural resources of great value from an area in a way that produces substandard levels of human welfare and of services for people who live there" (p. 6).

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<sup>20</sup>The original source of the culture of poverty thesis is Lewis (1966), who interpreted culture of poverty as "both an adaptation and a reaction of the poor to their marginal position in a class-stratified, highly individuated capitalistic society" (p. 21). For insightful discussions of the dangers of relying on cultural explanations for poverty, see Fisher (1976) and Ryan (1971).

<sup>21</sup>The historical roots of such assumptions can be found in local color writing of the 19th century (a pejorative tradition of writing about the "backward" ways of mountain people) as well as in accounts of missionaries, both of which portrayed Appalachia as a "strange land and a peculiar people" (Shapiro 1978).

<sup>22</sup>See Billings, Pudup, and Waller (1995) for a discussion of the various theoretical models that have been proposed.

Despite the work of contemporary researchers, stereotypes and cultural explanations for poverty persist. Pejorative accounts of Appalachian people can still be found in contemporary academic writing (e.g., Cattell-Gordon 1990) and popular culture (see Speer's (1993) discussion of the continuing problem of damaging mass media portrayals).

One of the few generalizations that one can safely make about Appalachia is that its people have had a long history of struggle against outside economic and political forces.

If Appalachia and its people are distinguished from other social groups, it is not in terms of personality traits, or even culture. What is significant about Appalachians is their history of systematic, routine oppression (Cable 1993, p. 69).

The historical roots of struggle date back to pre-industrial times when Appalachian families fought to preserve their way of life and adapt to the penetration of the capitalistic market economy that rendered their life as independent subsistence farmers less viable and increased their dependence on outside capital (Billings, Blee, and Swanson 1986).

For Central Appalachian communities, battles with the coal industry--for many years the dominant industry in the subregion--represent some of the most important and enduring struggles. From the 1880s to early 1920s, outside investors seized massive amounts of mountain land at low prices to develop the Appalachian coalfields. Company coal towns were erected during this period and town residents struggled to preserve their independence in a setting where the coal operators exercised power and control over almost all facets of everyday living.<sup>23</sup>

The most formidable restriction on the miner's freedom as well as the greatest source of power and authority over the miner was the company house, which gave operators the right to evict any worker at a moment's notice. With eviction came the simultaneous loss of job and of home; nothing could have been more traumatic. The company store also provided ample opportunity for exploitation through its scrip system<sup>24</sup> and, insofar as it provided the only outlet for essential items mining families needed for life and work, it could charge

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<sup>23</sup>See Shifflett (1991) for a social and cultural history of Appalachian coal mining towns. Another source for the social history of the early period is Corbin's (1981) study of southern West Virginia miners.

<sup>24</sup>Scrip refers to currency printed by the coal companies. Miners were paid in scrip and not in U.S. currency. Scrip was only redeemable by the company that printed it, so mining families were forced to purchase all goods from the company store.

whatever the traffic would bear. In addition, coal operators assisted in the development of schools and churches and the hiring of preachers and teachers, which presented them with the power to control public opinion (Shifflett 1991, p. xv-xvi).

Battles with the coal industry spanned many years and included labor issues--such as fighting exploitative and dangerous working conditions (e.g., Sessions and Ansley 1993) and seeking occupational health and black-lung compensation (e.g., Judkins 1993), and environmental issues--such as protecting the region's land from strip-mining (e.g., Bingman 1993), to name a few.<sup>25</sup>

Dealing with the consequences of massive job loss in the coal industry and the resulting effect on families and communities has been one of the most difficult and enduring struggles. Each generation has encountered significant structural reductions in employment in addition to minor layoffs resulting from the regular business cycle: the Depression, market changes, and the early stage of mechanization contributed to layoffs and short weeks in the 1930s;<sup>26</sup> another wave of mechanization displaced workers in the 1950s and 60s; the industry's loss of domestic and export markets and the declining price of coal precipitated plummeting employment and mine closings in the 1980s (Yarrow 1990). The Central Appalachian region was the hardest hit, losing more than 51 percent of its personal income from coal employment between 1979 and 1989 (Couto 1994).<sup>27</sup> The decline of employment opportunities is a major factor that has contributed to increases in the number of people in poverty and in the severity of their conditions.

Another enduring struggle faced by Appalachian people is the preponderance of substandard human services. Couto (1990, 1994) frames this problem as a lack of investment in social capital.

The human problems of the Appalachian region, and other areas of economic and social need, are, at root, problems of social capital: the investments a

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<sup>25</sup>Discussion of the innumerable historical and contemporary struggles facing Appalachian people is beyond the scope of this study. See Fisher (1993); Gaventa, Smith, and Willingham (1990); and Tice and Billings (1991) for examinations of crisis, struggle, and resistance in Appalachia. Fisher's (1993) volume includes a lengthy bibliography on dissent in Appalachia.

<sup>26</sup>Hill, Hirschman, and Bauman (1996) describe some of the many destructive consequences of coal town life during the Depression years as company towns collapsed and numerous families were evicted. For example, some families were forced to seek shelter in abandoned coke ovens.

<sup>27</sup>Couto's (1994) book offers an excellent discussion of Appalachian conditions as part of the social consequences of economic and political institutions, practices, and trends in America.

political body makes to produce and reproduce human beings in community. Private capital is the means by which we produce and distribute goods and services for individual and private profit. Social capital is the investment we place in health care, education, housing, culture, the environment, and other factors to produce and reproduce people and their community (1994, p. 9).

Social capital investments in Appalachia have historically been driven by the needs of the dominant industry, primarily the need to maintain a productive labor force. As coal companies downsized and closed, communities experienced a corresponding decline in social capital that persists today (Couto 1990, 1994).

Like many Central Appalachian communities, Fairmount County is plagued by poverty-stricken living conditions and substandard social capital investments, both of which serve as risks to poor health. The next section explores both environmental and institutional barriers to health care delivery in Fairmount County.

### **Risks of Poor Health in Fairmount County**

By almost every indicator, Fairmount County residents experience poorer health outcomes than residents of most other parts of the state. The county has higher rates of heart disease, chronic obstructive pulmonary disease, pneumonia, and black lung disease. County residents also experience higher rates of cervix, breast, lung, and colo-rectal cancers as well as a suicide rate 1.5 times higher than other areas of the state. Further, the state's coal counties have higher rates of injury, long term illness, and disability.<sup>28</sup>

What are some of the risks that contribute to such poor health outcomes for Fairmount County residents? Informants cited numerous environmental and institutional barriers to health care access and good health. This remainder of this chapter explores three general areas of health risks: economic constraints, environmental and occupational risks, and maldistribution of providers and services. Consistent with my research objectives, the data show that women in this study did indeed face multiple vulnerabilities to poor health.

#### **Economic Constraints**

*Jobs, Income, and Insurance.* Poverty is a way of life in Fairmount County, and the daily struggle of living in poverty was at the center of the women's discussions of health care. They relayed many ways that poverty affects their daily lives, health status, and health care

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<sup>28</sup>Citations not included to protect identity of county. Sources include reports from regional health planning district and university extension office.

access. The most frequently mentioned economic issues were the lack of jobs and no or inadequate health insurance.

There is just no jobs in this area. So anybody that wants to get out of school and go to work, or start a family around here, it's not very hopeful, I guess. (Interview with Kathy)

I've seen too many people and hear too many people talk about this area, you know, that, I mean like right now I'd give anything in the world if I could find a job. But you can't find 'em close enough to pay you to drive an hour, hour and a half away, on gas and everything. I mean. (Focus Group 4)

At the Fairmount Clinic, they won't take you in if you don't have money. No matter how sick you is. No. Some of these people, they don't have uh money or insurance and things. It's just jobs is, the mines closed down, they lost all their insurance. (Interview with Martha)

Most of the people around here are very poor. They live on a limited income. A lot of them all they have is Medicare, and Medicare doesn't pay everything. (Interview with Anita)

Thus the women fully understood the economic depression of their community and the connection between these economic conditions and health care access.

Providers, too, recognized how adverse financial situations prevent many women from accessing the health care system.

And the other causes, reasons why they don't come see a doctor, especially in rural area here is the financial situation. People most of them don't have insurance here and they don't have money you know. I really uh was surprised that some people they don't have a dollar in their pocket to spend you know. That is one of the biggest reasons why they don't come and see the doctor because they cannot afford to. Even paying five dollars realizing this clinic this is a federally funded clinic and we take care of indigent people. But, and some people who are on sliding fee A and B and C like here they have to pay five dollars--they don't have five dollars to pay and they're so embarrassed to come because they cannot afford it. (Interview with Dr. Alloju)

Financial [is a constraint of practicing medicine in this area], you know. We have a lot of people in the area who don't have insurance who are constrained on uh finances in terms of uh even coming to see a physician. And then once you are here, you write a prescription, they have difficulty having the uh prescription filled. (Interview with Dr. Thomson)

Compared to the state as a whole, the coal counties in the state are characterized by two-thirds more poverty and even greater unemployment, underemployment, and undereducation (University Extension Report). The percentage of Fairmount County residents below the poverty line is 25.9 (1990 Census). The county's 1994 average unemployment rate was 16.2 percent, almost three times the rate for the state (State Employment Commission). Further, area incomes have not kept up with the national cost of living. Despite attempts by the county Board of Supervisors to attract manufacturing and commerce, few new employers have located in the area; those companies that have are light manufacturers that provide part-time and/or low-paying jobs with few or no benefits.<sup>29</sup> And, of course, compounding the economic depression of the region is the decline of the coal industry and the secondary industries it once attracted, leading to persistent employment uncertainty. All of these problems combine to form "... a vicious circle, depriving residents of good job opportunities and discouraging potential industry" (Regional Health Planning District Report).

Weiss (1990) discusses how the type of jobs traditionally available to women can also contribute to poverty.

...the kinds of jobs that [women] are encouraged--sometimes forced--to take are occupationally segregated, a pattern that reserves for men jobs in technical and industrial fields that are well paid, unionized, and carry unemployment compensation when the going gets rough. 'Women's jobs' are in the service sector and are likely to be dead end, low paying, and nonunionized. Many of these jobs are part time and seasonal, and the alternative is welfare (p. 62).

This state of affairs is consistent with the data I collected during my fieldwork. Most of the women I met had either 1) low paying jobs with no benefits and little hope of advancement, such as jobs at the local sewing factory or in the service industry, 2) jobs in the informal economy,<sup>30</sup> such as selling produce and other goods at flea markets, sewing, cleaning homes, or providing child or elder care, or 3) part-time jobs. Of course, few of the service industry jobs and none of the part-time or informal sector jobs provide health insurance. One informant who works part-time for a community service organization described how her low income often means doing without health care.

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<sup>29</sup>Personal conversation with candidate for Board of Supervisors.

<sup>30</sup>In the informal sector of the economy, individuals improvise to find work when no jobs are available in the formal sector. In rural communities, a vast informal economy exists that is run primarily by women. The informal economy "is largely unregulated, its practitioners are often highly entrepreneurial, and it is, especially for women, highly exploitative" (Weiss 1990, p. 65).

Fran stated that working part-time for \$5 an hour, and having to provide for her family, meant she didn't even have an extra \$14 to cover the cost of a pap smear (the sliding fee charge at the Health Department). 'I just didn't go. I just didn't have it. I didn't even have an extra *five* dollars to do no pap smear.' (Fieldnotes 6/28/95)

*Transportation.* The rural isolation of the county and the associated transportation barriers is another factor that can adversely affect health care access. Fairmount County is located in a mountainous region in Central Appalachia, isolated by terrain, a lack of major highways, and no public transportation. Distances are great and travel is difficult for many residents. Narrow, winding roads present hazards, particularly during icy weather.

And many of them can get maybe two miles out of the holler to the main road, but they can't get all the way to Casserville, you know. That's 20 miles. (Interview with Ms. Rinker)

We don't have public transportation. Almost anything people do, they have to do by private automobile, and distances are great. In bad weather, travel is slow. (Interview with Dr. Robertson)

...one concern of patients because of the road, especially when it snows or when it's icy. When it snows in this area either they can't get down because the roadway slippery or they can't get up. And the nearest hospital in the area is 30 miles, 30 minutes away. That's again because of the terrain. Sometimes we have to call for helicopter if we have uh severe emergencies. (Interview with Dr. Chavda)

## **Environmental and Occupational Risks**

Dangers in the living environment also served as risks to poor health. For example, contaminated water and air pollution were commonly cited as health risks.

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. [Moderator: Could you describe the kind of sewage system?] Well it goes right into the creek bed and then it goes to the river. And, 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.... And sometimes it has enough chlorine in it to kill anything. (Focus Group 3)

Everything we got comes from this water. And you know what a health hazard that is.... We don't have septic tanks. We ain't got no sewer system. It dumps right out here in this creek.<sup>31</sup> (Interview with JoAnn)

The Marsh Creek volunteers warned me on my first day here not to drink the water. I've noticed since then that some people use bottled water. Today one informant told me about a place in Kentucky that she goes to get free spring water. (Fieldnotes 6/8/95)

A lot of water is contaminated here and that causes a lot of health problems. Uh you know people live next to coal mines here sometimes and that you know will affect the atmosphere and cause more problems. In this area lung cancer is very common here or cancer in general is common in this area. I think it has something to do with, it probably has to do with coal mines, and this you know air pollution.... (Interview with Dr. Alloju)

In addition to contaminated water and air pollution, overcrowded and substandard housing was also a problem.

...another uh, uh concern about me is housing for people. You know when we say homeless, it's not homeless just the man out in the street. There's homeless when you got a three room house and you got six people living in there. And it's homeless when you got a house and have extra rooms and HUD is paying your rent and your children can't stay there. HUD pays my rent and Tina stays with me and my son stays with me. But if HUD know that they would tell me that they can't no longer stay here. That's homeless. Because I got that room, two rooms upstairs and not bothering anybody. But Tina or Craig is not allowed to be in this house. They do not know that those people are staying here. (Focus Group 1)

Environmental stress [can also cause people to be sick] like, their houses are not insulated uh, they have no central heating. Or plumbing. (Interview with Ms. Rinker)

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<sup>31</sup>JoAnn also discussed the contradiction of how dirty water conditions persist in the county, yet the county is promoting itself as a prime white water rafting destination. "And they say that white water rafting is the best we've got in the state. Well this is dumping right in on them. You know, at the radio meeting, I asked the men who work here, they were promoting, spending all these thousands of dollars to promote that white water rafting, and the sewer is dumping on it. They wouldn't really want people to know the sewer is dumping in on that."

The houses in Oakwood are in deplorable condition--rotting roofs, peeling paint, and many other signs of disrepair. Lynn [the Marsh Creek Center staff member in charge of housing issues] told me that two of the houses are slated to be repaired later this month by college student volunteers coming to the area for an Appalachian Experience. (Fieldnotes 6/5/95)

Sharply rising housing costs combined with declining incomes have contributed to a growing crisis in housing affordability. The availability of Section 8 housing is decreasing as many owners refuse to rent through Section 8 because of reduced fair market rent. Similarly, the number of single family houses has steadily declined over the last decade. Existing housing units are frequently old and substandard, and safe water and suitable waste water systems remain ongoing problems (People Inc. 1994).

Local occupational hazards also presented health risks. Many of the women's husbands and fathers (and a few of the women) used to work in the coal mines. The women detailed the numerous health hazards associated with coal mining, particularly respiratory problems such as black lung.

They pulled him out of the mines about 10 years ago. The doctors pulled him out of the mines because of his lungs.... He's got so many [problems from working in the mines].... He's got black lung. From the mines.... He's had three light heart attacks.... He is on a stomach pill for ulcers.... He is a real nervous type person. (Interview with Helen)

Black lung ("coal workers' pneumoconiosis" in medical terminology) is a chronic dust disease of the lungs stemming from working in an underground coal mine (Judkins 1993). Lung disease is one of the seven leading causes of death in the local area (Regional Health Planning District Report).

The local sewing factory, too, presented occupational hazards. One informant described the adverse working conditions she faced.

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)

Other informants described the adverse consequences of sewing factory injuries.

My daughter, she's 43, my youngest daughter, and her spine is ah, the vertebraes in her back have been pulled far enough apart from her work 'til they disabled her, and you can stick your hand back between.... A box of coats fell and hit her in the back. And it pulled them vertebraes loose in her back and she's been disabled ever since.... And she's drawing disabled Social Security. But, you know kids do get hurt on their jobs and ah, it, it does make problems for their family as well.... And uh she can't help [her son]. Cause she can't get out to work. And then she would do more for me if she could, but she can't. (Focus Group 3)

I've got one patient who is working at the sewing factory up here. She had finished her shift and walked out to go home and on the way out there was a step which was really a cinder block. And the cinder block threw(?) her. That's been 13 or 14 years ago. She can hardly walk and she is still in pain all the time. And most of these people I see have been uh to physical therapy. (Interview with Dr. Thomson)

Community obstacles to healthy behaviors were also identified as problems. The women fully understood the importance of regular exercise and balanced diets, but encountered numerous community obstacles to adopting healthy behaviors. One of the chief obstacles they complained about was the lack of places to walk--parks and walking trails are nonexistent in the county. To make matters worse, walking on the street is hazardous because one might encounter a "coal truck experience."<sup>32</sup>

I doubt that anybody in this community gets enough exercise though, do you? There's not a walk, well if you're walk, if you'd walk, you're in traffic and you got to dodge something all the time. (Focus Group 3)

But up there, there, because of the coal trucks are so big they hog the road so you normally got to go over the hill to get out of their way. So this road really isn't any walking places. (Interview with Fran)

There's too much traffic.... You've got to watch. Cause these coal trucks, they fly through here. (Interview with Helen)

Similarly, the women encountered obstacles to developing good eating habits. I observed during fieldwork that fresh produce was difficult to find in the grocery stores and local restaurants had few healthy menu choices. In fact, one local restaurant known for its

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<sup>32</sup>This is a common phrase I heard during fieldwork. It refers to coal trucks barreling down the narrow, windy mountain roads.

down home country cooking had no healthy choices; to the contrary, every dish was high in fat content! The women also noted how prevalent it is in the community to cook with "fatback" or lard because it is cheaper than shortening. They recognized how this makes healthy eating habits difficult and can contribute to poor health.

People just, my mother-in-law cooks with lard. I mean she can make the best pinto beans in this world. But they are full of lard. And it's just like mmm, but that is how she was brought up to cook. Well, if she was like me, 200 plus pounds, she don't need to be cooking with lard. If she has heart problems, she don't need to be cooking with lard. But it is a cheaper shortening for this area. (Interview with Kathy)

It's the fatback, honey [that makes our diets poor. My relatives say] 'Sit right there at that table, put that grease on them biscuits, and eat it right up.' (Focus Group 2)

I never cooked with fatback in my life, my mother-in-law puts grease in anything. (Focus Group 5)

Thus, it was difficult for the women to avoid high fat foods in their daily lives, such as while eating at the homes of friends and family. The women also implicated the role of individual behavior in dietary habits.

Watching my diet [is hard] because I'm a sweetaholic. (Interview with Kathy)

I know all the [nutrition] rules and I've broken 'em all, honey. (Focus Group 5)

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)

However, in contrast to the women who identified both individual *and* structural obstacles to healthy behaviors, most of the providers attributed poor exercise and eating habits only to individual behaviors and lack of knowledge of healthy behaviors.

They get sick, I think, because of improper nutrition, because of lack of knowledge.... These people need to know, they don't understand, they don't comprehend, they have probably never been told and if they have been told, they didn't understand the importance of a balanced diet, proper hygiene, and that type of thing. (Interview with Mr. Vega)

[What is needed is] educating the women in the community. The importance of regular check ups, diet, exercise, and wellness. (Interview with Nurse Martin)

Thus, many local economic and environmental barriers to good health existed including lack of jobs and insurance, contaminated water, air pollution, substandard and overcrowded housing, occupational hazards, and community obstacles to healthy behaviors. In addition to environmental barriers, informants identified numerous institutional factors inherent in the health care system that limit health care access. One of the greatest barriers was the maldistribution of providers and services, discussed in the following section.

### **Provider and Service Distribution**

As noted earlier, an enduring struggle facing Appalachian communities is their fight to deal with substandard social capital. As coal companies left Fairmount County, so did social capital investments in health care. This condition, coupled with the remote location of the county, results in limited access to health providers and services. Fairmount County is federally designated as a medically underserved area, with a physician:client ratio of 1:2937--quite a contrast to the national ratio of 1:704 (State Primary Care Association). It is also classified by the state as a health professional shortage area. Only six primary care physicians practice in the county. Further, no local specialists are available in the areas of obstetrics/gynecology, orthopedics, cardiology, or cancer. Unavailability of these services puts a tremendous burden on Fairmount County residents; some people travel great distances to obtain needed services, while others cannot afford to do so and suffer the results of poor health.

Access to providers is a particularly relevant problem for many vulnerable populations. Rural populations depend on primary care providers for most health care needs, but a shortage of primary care physicians exists across the United States, particularly in rural communities (Fickenscher 1992). Scammon, Li, and Williams (1995) suggest some key structural barriers that help explain why few providers choose primary care and/or choose to work in rural communities: medical schools are dominated by subspecialty curricula, medical students have little exposure to primary care role models and little opportunity to train in settings other than that of highly specialized university medical schools, and the salary differentials between generalists and specialists are large.

*Maldistribution of Providers.* Informants lamented the limited availability of both family practitioners and specialists.

Access to a specialist is a problem. We always have to go like 75 to 100 miles to the tri cities area.... We really have no pediatricians in the county. That is a real problem for young mothers. And to travel out of the county.... There is a

problem with gynecologist and obstetrical care. I mean you have to travel...40 miles away to see a gynecologist. (Interview with Ms. Rinker)

There is not always the capacity to get to Ellet City or Windsor to the specialty doctors.... We need more specialty doctors in this area. It would be great if we had pediatricians. It would be great if we had geriatric, that just concentrated on that. And OB/GYN, eyes, ears, nose, and throat. Just in this area. But it's a long time coming, I'm afraid. (Interview with Kathy)

Further, some of the few specialists that do serve the county only do so on a weekly or biweekly basis. For instance, the dentist and the cardiologist were only available once a week. The women discussed the adverse consequences of such limited availability of providers:

There's one dentist in Easy Rock that you can go to. He's only there on Wednesdays and you're lucky to get an appointment in. And you know how far it is you have to go. And...it's expensive. (Focus Group 3)

There's a lot of people that have cancer at the mouth.... Or people lose their teeth because of that. I mean, we have young kids that coming up that have problems with toothaches. And that's terrible because you don't have a dentist to take your child to. (Focus Group 1)

[The cardiologist] comes once a week. Well, if you have something really bad wrong with your heart, and something goes wrong, you can't wait till next Thursday when Dr. \_\_\_\_\_ is coming. You know, you need help right now. And Casserville [the county seat--where the cardiologist visits] is only eleven miles away. [The cardiologist's office] is about 70. (Interview with Anita)

As noted, six primary care physicians (PCPs) practice in the county and few specialists are available. However, only half of the PCPs were trained as family practitioners. (The others were trained in general surgery and internal medicine.)

*Recruitment and Retention of Physicians.* Recruiting and retaining physicians in Fairmount County is extremely difficult.

They [the county] have not been able to retain doctors. Doctors here stay only one year and then move again. Most of the doctors who, what do you call them now, they want to pay their loan to the government. They are made to work in the rural areas for a year. After their service for one year then they move on. This has been the condition of this area. (Interview with Dr. Chavda)

Both the women and providers expressed concern about the difficulties of attracting and retaining doctors in their community. The lack of business and infrastructure development were two reasons cited for why doctors do not stay in the area.

[To recruit and/or retain] more doctors, uh, improve the economy in here. Since I started here I knew already that unless the access roads in here is improved, the economy will not improve. They cannot attract uh industries. They cannot attract uh doctors.... Mmm if we could have the coalfield expressway, that's our only hope. Otherwise uh no doctor will be attracted to stay here. (Interview with Dr. Chavda)

In addition, the rurally isolated county lacks the normal amenities found in other areas.

They never could keep a doctor down there. They would get a couple of doctors in and every time--usually doctors when they move in here they will stay like a year or two. They leave because there is no convenience. I know you can see that there is no convenience. But it is better than it used to be. At least you can go to Bendersville. And the doctors just won't stay because of the inconvenience of the area. It takes you so long because of the roads to get anywhere. You don't have any, like, shopping malls or anything to go to. Which their wives are discontent. I can understand why. (Interview with Rita)

And that's one of the problems you know. [Doctors'] wives don't want to stay in this area. Why? First we don't have good recreational facilities in this area. Second, if you want to go places you have to drive two or three hours you know to go a place like a mall you know. And most women like to go to the mall when they have the money.... And uh and then of course the children you know, they, they like to live in you know a more convenient city you know. And basically recreation here is almost nil.... And ... we have no good roads in this area. We need that you know so that we can easily go from one place to another. (Interview with Dr. Sandoral)

The high percentage of Medicaid patients in the area was also mentioned as a deterrent to recruiting doctors.

As far as finding people [doctors], offering them opportunities to practice in the area, and things like that, payment is a problem. Because a lot of our people [local residents] are with Medicaid coverage which does not pay as much as physicians feel like they should pay. Some of the doctors say somebody comes to them every month and asks how much is Medicaid, how much is Medicare, how much is unpaid, and they say good bye. So the payment of physicians is a

problem. If health care reform comes, and everybody is being paid the same every place, maybe that will help. (Interview with Dr. Robertson)

*Unavailable Services.* Another institutional barrier that impeded the women's health care access was that many needed health care services were not available in Fairmount County, such as cancer and cardiac services.

Ah, for cancer, for heart attacks, something really major, ah, we do not have the facilities. No, this is my personal opinion. Ah, but we do not have the facilities in this area... We had to go to Windsor,... we're talking two and a half hours away. (Focus Group 5)

Obstetrical and gynecological services were also not available locally. For instance, woman had to travel outside of the county (one or more hours) to deliver babies or to obtain prenatal services.

It would be nice if the hospital, when they built it, was fixed for having babies, and do more surgeries. And stuff like that. And it would be nice if they had classes how to take care of your newborn. I mean they teach in the hospital but women has a vaginal delivery now don't stay two or three days. So how much are they going to pick up? (Interview with Kathy)

One woman commented on how the concentration of services in larger metropolitan areas means that this county is forgotten in the distribution of health services. She stressed the need for more equitable service distribution.

They forget about Fairmount County. They stop in Windsor or they'll stop in Ellet City.... We always get the tail end for everything anyway in Fairmount County. I would like to see...to fix it where that, there's an equal space where people can get to and from it. And if necessary transportation. (Focus Group 1)

For those services that are available locally, most of them are in the county seat, which is still quite a distance from many local residents, as much as an hour on windy, mountain roads.

### **The Importance of Community**

In contrast to these difficult struggles, one affirming, positive aspect of Appalachian life is the strength of community. Against this backdrop of historical and enduring struggles including the fight for health given inadequate social capital investments, community has emerged as an important concept for understanding how people in Appalachia handle the

struggles. That is, community is a basis of unity as people fight commonly shared struggles and community helps support them during such times. While a variety of perspectives on community exist,<sup>33</sup> Beaver (1986) suggests that community is more than a geographical entity. "It is also an ideological entity--a body of individuals whose members are linked by kinship relations, historical events, and the requirements of making a living" (Beaver 1986, p. 140-141).

Closely linked to community is family. Family and kinship are core values within mountain communities (e.g., Beaver 1986; Bryant 1981; Schwarzweller, Brown, and Mangalam 1971). Beaver's (1986) work celebrates family and community and discusses how kinship ties give individuals identity, provide the basis for social networks, and unite communities. First, through kinship ties people share common roots, experiences, and values which give them a sense of who they are (Beaver 1986). Within Appalachia, the family land also contributes to this identity. Individuals are the stewards of the land and in return the land offers stability and personal identity (Eller 1982). Second, family ties provide a foundation for broader social and community networks (Batteau 1982; Beaver 1986). Such networks provide a basis for reciprocal exchange and assistance (Beaver 1986). Third, kinship networks serve to bind communities together. Kinship "is more than biological or genealogical connectedness; it is a cultural idea through which relationships are expressed and from which community homogeneity is derived" (Beaver 1986, p. xx). Social relationships in mountain communities tend to exhibit characteristics of family relationships (Schwarzweller et al. 1971).

Most of our people here in our community, mostly it's basically like everybody's uh family, you know. Everybody really cares about everybody. Even though we disagree sometimes. But when you get down to it everybody here really loves everybody. And you worry not just really about yourself but everybody else in your community. (Focus Group 1)

This research found that *shared experiences and struggles* do contribute to the development of community. Coming together to address common struggles was a prevalent theme in the data.

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<sup>33</sup>Research into the nature of mountain communities reflects a split tradition, with some authors focusing on individualism and others on community. Eller (1987) stresses that both individualism and community are a part of Appalachia's (and America's) common heritage. "Americans have always spoken a dual language--one rooted in images of radical individualism, private achievement, personal consumption, and individual success; the other in images of civic responsibility, social equality, public virtue, and commitment" (Eller 1987, p. 150).

The coal camp of Oakwood is a legend. Oakwood residents are known for being proactive and for the way its residents band together as a united front to address issues facing the community. For example, when the local post office threatened to close, community residents banded together to prevent this from happening. Likewise, Oakwood residents had to fight together to obtain needed sewer and water lines. The most well known success is when the town was being sold and Oakwood citizens successfully fended off corporate buyers and kept their homes. (Fieldnotes 3/20/95)

They really help you whatever you need. They try to provide. Just like when the economy here started to go down because of the closing of the mines, when I was running this clinic myself and the income was getting lower and lower until I can't pay the overhead expenses anymore. So, I told the, my community, the area cannot support the clinic and I have to go. And they said 'We want you here, we appreciate what you have done to the community, so stay as long as you can and we will see what we can do.' So the whole community moved and they were able to find [a sponsoring organization] to help this kind of grant. We asked their help and then they tried to help us with the grant. (Interview with Dr. Chavda)

The Fairmount County Women's Health Collective (discussed in the methods chapter) is another example of people banding together to solve a common problem.

Further, community networks and support systems also helped to sustain people during times of struggle (Fisher 1993). Mutual aid and support were prevalent practices for providing such sustenance.

And I thank God for Vicky, she helped me so much. We drove back and forth to, for our [cancer] treatments some, and I think we leaned on each other. We, we drew strength through each other, we, we really did. And developed such a close friendship. And ah, so I think we helped each other, I know she really helped me. (Focus Group 5)

You can just go to anybody in the county if you needed help, and they would, they would support you. They would do what they can for you. (Focus Group 5)

People in this area, if you say, if they know you are having a hard time, or times are pretty rough for you, because it is kind of personable, they just seem to be quicker to help [than the other places she has lived]. (Interview with Kathy)

I'll tell you somebody else that is a blessing to me too, is Christina. Now she will come and she go to the store or something, she'll come and ask me if I want anything at the store. And, 'Do you need anything? How are you feeling?' And I told her, I said 'Honey, you never know how much I appreciate that.' Cause my daughter lives in Berrysville where she is not able to come over until sometime on the weekend. (Interview with Paula)

The cancer support group meeting I attended tonight had one of the warmest, most supportive, most encouraging atmospheres I have ever experienced. One of the women that shared with the group told how when she was diagnosed with cancer, she was amazed and delighted at the large number of women who called her to offer their support and encouragement. It really helped her to get through the tough days. (Fieldnotes 6/6/95)

This finding is consistent with Beaver (1986), who suggests that community and kinship ties serve as a basis for how people should behave toward one another, including norms of reciprocity and mutual aid.

Another strong expectation was egalitarianism. One example of this expectation was the belief that low income people should be treated fairly and with dignity and respect. Informants resented people who looked down on them or treated them unfairly.

I don't like being poor. I don't like the way people treat you, you know.... I can take being poor, but the way people treat you! ... It's not a handout, just a hand. Just to help you to get back up on your feet. (Focus Group 1)

A lot of them [social service providers] try to make you feel like it's coming directly out their pocket. Like they got to go and write a personal check out their own pocket. That if it wasn't for poor people like us they wouldn't have a job, you know what I'm saying? (Focus Group 1)

Unfortunately for the women, they felt little respect during interactions with health and social service providers.

You tell them your kids are on Medicaid, they are instantly, or I feel like, maybe it's stereotyping, but lone street urchins that are dirty, or live in a dirty and nasty home that the parents don't care. (Interview with Kathy)

He was totally rude, calloused, and very aware that I had Medicaid. And I'm sure that's why I got treated like that. I'm positive. (Interview with Rhonda)

These expectations for egalitarianism reflected fundamental beliefs in fairness, social justice, and the worth of individuals.

These findings are consistent with other research that has found egalitarianism to be an important cultural value that influences interpersonal relationships in Appalachia (Beaver 1978, 1986; Cable 1993; Fiene 1990, 1991, 1993; Keefe 1988; Schwarzweller, Brown, and Mangalam 1971). The roots of the egalitarian ethic arise from the need for rural communities to maintain cooperative behaviors (Beaver 1986).

Beaver (1986) found several leveling mechanisms operating in the Appalachian community she studied that encouraged conformity to the ideal of egalitarianism: 1) collective history and shared experience, 2) self-denigration (e.g., "We're all just plain mountain folks"), 3) avoidance of display, and 4) chastising those who deviated from the egalitarian principle (e.g., those who were "uppity"). Latter mechanisms were based on the desire to be inconspicuous, and served to reaffirm a social order based on relationships rather than on competition and material wealth (Beaver 1986).

In summary, Appalachian people have a long history of struggle against structural forces such as exploitation and absentee ownership of the area's land and resources, plummeting employment, and substandard investments in social capital. Inadequate investments in health care are in part reflected in the maldistribution of providers and services in Fairmount County. Compounding this barrier to health care access are the numerous economic and environmental risks of poor health facing area residents. Obtaining health care is thus a struggle. The importance of community emerges against this backdrop of struggle. Shared experiences and struggles can serve as bases for the development of community. Further, community networks and support systems help to sustain people during times of struggle (Fisher 1993). Two core values related to community are kinship and egalitarianism. Kinship ties provide identity, serve as the basis for social networks, and bind communities together. An ethic of egalitarianism, grounded in a fundamental belief in fairness, social justice, and individual worth, influences expectations for interpersonal interactions.

## **PART TWO**

### **THE SERVICE ENCOUNTER**

Why are consumers in Fairmount County at such risk for poor health? Chapter 3 explored economic constraints, environmental and occupational risks, and provider and service distribution barriers that impact health care access and outcomes.

Part II, "The Service Encounter" examines health care delivery in Fairmount County through the voices of the physicians (Chapter 4) and the voices of the women (Chapter 5). These two chapters reveal uneasy tensions in health care delivery in the community and shed light on why the health care needs of vulnerable populations are not being adequately addressed. Then, Chapter 6 highlights the contradictions that emerged from the stories of the women and providers. It illustrates how problems in health care delivery in this community exist at a higher level than just the immediate medical service encounter--problems stem from a collision of two cultures.

## CHAPTER FOUR

### THE VOICES OF THE DOCTORS

This chapter explores health care delivery in Fairmount County through the voices of the physicians. An analysis of these voices suggests that the dominant curing model of the health care system permeates the doctors' attitudes and delivery of health care. This chapter begins by describing the dominant medical paradigm--the curing orientation. It then explores how, despite the doctors' caring impulses, the dominant medical model permeates their practice of medicine. The doctors suggest that their medical training ill prepared them to deal with the realities of working in an impoverished community. In the final section, the role of the physician in the service encounter is explored.

#### **The Dominant Medical Paradigm: The Curing Orientation**

The social structure, culture, policies, and practices of the United States health care system are largely driven by a "curing" model of health care that focuses on disease and emphasizes technology-driven diagnosis, treatment, and intervention. This approach frequently leads to health care providers viewing patients as the disease (i.e., "the lymphoma in Room 304") instead of as human beings (Conrad 1988). The historical roots of this disease-centered orientation lie in the great medical breakthroughs of the latter part of the 19th century. These medical advances vindicated the metaphor of the body as a malfunctioning machine and the germ theory of disease (Conrad and Schneider 1986). Thus, this approach of focusing on the disease largely in isolation of the whole person and the environment has a long medical tradition.

In contrast to the curing model, a caring model of health care focuses on the whole patient, not just her disease. Taking a whole patient perspective means attending not only to a consumer's disease but to her *experience of illness*.

Varying terms are used by social scientists to capture this familiar distinction, but the general meaning is clear enough. The patient's disease is what the doctor pronounces; it is the pathological entity, the CAT-scanned lesion, the biopsied tissue, or the blood-gas chromatograph that objectifies the patient's distress.... Standing in contrast to the patient's disease is the patient's illness--the pain and sense of unease, the symptoms and self-observations, the sense of self altered under the impact of illness. Although the disease is not the same as the illness, the latter can accommodate to encompass (or to reject) what the doctor avers as the truth--the biomedically characterized disease (Gallagher 1993, p. ix-x).

In short, a curing orientation to health care delivery objectifies the consumer by focusing on the *disease* and assuming that it can be treated in isolation from the patient. On the other hand, a caring orientation attends to the consumer's social and emotional needs as well as the disease, and focuses on healing the *person*.<sup>34</sup>

While some health care providers do adopt a caring orientation, the curing model permeates the health care system. This disease-centered orientation is reified in the structure, culture, and practices of the medical establishment. In particular, it is manifest in 1) the technological favoritism of the medical care system, 2) the proliferation of medical specialists, and 3) the medical school education and socialization process. The curing orientation may foster an impersonal treatment of consumers.

First, the technological favoritism of our health care system is one example of how the curing model is entrenched in the structure and practices of the medical establishment: technology advances medicine and technology solves medical problems. A widespread belief exists that the quality of health care improves with higher levels of technology. Wright (1989) refers to this perception as "technophilia" or "a Western faith in the usefulness and benevolence of medical technology" (p. 13). Technophilia has a long history in the medical establishment. For instance, almost thirty years ago, Fuchs (1968) discussed the "technological imperative" of medicine that equated the quality of care with what was technologically possible. However, the financial and human resources invested in the production of new medical technologies through the years have not been matched by a corresponding investment in evaluating their usefulness or appropriateness (Price 1989). Further, high technology often results in depersonalization of the medical service encounter. Bayles (1981) argues that physicians have become mere technicians or "body mechanics," treating the affliction but not the person. Similarly, Evans (1993) suggests that the increasing availability of medical instruments leads to a focus on what is seen and measured instead of what is felt and experienced, creating "a cold and impersonal chasm between the healer and the patient" (Evans 1993, p. 82). The medical encounter is a *cold* encounter.

A second manifestation of the disease orientation is the proliferation of medical specialists. About 80 percent of physicians are specialists, despite the fact that only 20 percent of illnesses require a specialist's attention (Light 1988). One factor contributing to overspecialization is physicians' historical bias toward the most "professionally interesting" care, regardless of cost or need (Light 1988; Twaddle and Hessler 1987). A second driving factor is the increasing complexity of modern medicine, which has forced many medical students to concentrate on isolated parts of the body. However, specialization can lead to

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<sup>34</sup>Other terms have been used to refer to this distinction, such as disease-centered versus patient-centered care (Frankel and Beckman 1989) and technical doctoring versus humanistic care (Conrad 1988). These terms are used interchangeably.

fragmented care with fewer and fewer doctors taking responsibility for the "whole" patient (Fuchs 1974; Light 1988). The structure of medical education and rewards also drives the trend toward specialization and subspecialization. Medical schools are dominated by subspecialty curricula, students have little exposure to primary care role models and little opportunity to train in settings other than that of highly specialized university medical schools, and the salary differentials between generalists and specialists are large (Scammon, Li, and Williams 1995).

The medical school education and socialization process is a third manifestation of the curing orientation. While many critics call for a more consumer-responsive health care system, medical schools have not heeded this call. Rather, the structure and rewards of medical education continue to be shaped by the dominant curing paradigm; that is, the priorities of academic medicine stress medical research advances such as new clinical techniques, medical devices, and drugs (Lewis and Sheps 1983; Ludmerer 1985; Light 1988). Thus, teaching medical students "often occupies last place in the competition for faculty time and attention" (AAMC 1984, p. 15) and the development of interpersonal skills is given scant attention (Huddle 1991). Several studies suggest that medical education fosters an impersonal, often negative, attitude toward patients (e.g., Conrad 1988; Coombs 1978; Mizrahi 1986; Scully 1980). For instance, Coombs (1978) found that faculty in a California medical school provided minimal guidance about how to handle interpersonal interactions with patients. Rather, the faculty members served as role models for emotional control and a businesslike demeanor. Similarly, Mizrahi (1986) found that house staff members in a large university medical center socialized residents into a "get rid of patients" (GROP) perspective during residency training.

The remainder of this chapter explores how the curing orientation is manifest in the attitudes and practices of Fairmount County physicians.

### **Health Care Delivery in Fairmount County**

Consistent with the literature, the curing model of health care permeated Fairmount County physicians' orientations toward consumers and health care delivery. Nevertheless, the curing model ill prepared the physicians to deal with the realities of rural medicine and vulnerable consumers. First, the doctors were trained and socialized to provide highly specialized care that was dependent on the latest medical technology--a type of care that was often far removed from the realities of practicing in an impoverished community with limited resources. Second, the physicians exhibited a disease-orientation by isolating the illness from the person and her social context. Thus, the service encounter was a one-way, physician-dominated experience with little attention given to consumer needs or concerns.

## **Technology-Based, Specialized Training vs. Human-Based, General Practice**

In many instances, the high tech, specialized training Fairmount County physicians received in medical school did not adequately prepare them for the realities of practicing in an impoverished, medically underserved community. The medicine practiced in Fairmount County could not rely on the most recent technological advances, but instead was driven by the skills of the doctor, skills that included adapting to limited resources and communicating interpersonally. Further, the high tech, specialized training did not prepare doctors for the *general* practice of medicine and preventive care that they encountered.

*Practicing Medicine without Technology.* One problem was that medical school training is largely based on unlimited access to resources and technology. Thus, the medical skills needed to practice without such resources are undeveloped. For instance, one physician discussed how medical students are trained and socialized that good diagnoses depend on and are supported by laboratory tests, which is consistent with the curing orientation. However, given that such resources are often nonexistent in an area like Fairmount County, the doctors usually had to make diagnoses without this support.

When you're in a university center and when you're exposed to university medicine only, the training is extremely technical, and it's assumed, it is assumed, because it's true, that everything that you could conceivably want to order is there. If you want some sort of esoteric test that might take 48 hour urines or something like that, it's easy to do. Because they're there. Here that's not true, and when you come out of med school you're all prepared to 'I'm gonna go and do this, and be the best possible physician I can be' and that is trained into you throughout school that that's based on testing, and diagnostic procedures. OK, then you get to an area like this where they're not available and you're kind of stuck for a while and you find you've got to use your ears and eyes a lot more than you do in med school. And that's, it's, it's just an important thing I think to be exposed to the type of medicine that we practice.  
(Dr. Waters)

Dr. Sandoral mentioned how *challenging* it was to work with limited resources and be forced to rely on his skills.

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. But I think we are able to overcome that you know by, by being able to know what our available resources in the area.  
(Dr. Sandoral)

But operating under the constraint of limited resources was also frustrating for local physicians. Because certain specialized services were unavailable, doctors were often forced to send patients outside of the county. (This alternative was problematic because many Fairmount County residents did not have the financial or transportation resources to seek care outside of the county.)

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. (Dr. Chavda)

Dr. Waters expressed similar frustrations about sending people out of the county, but also noted that the highest level of technology and technical care was *not always necessary*.

Um, there are services we need. That, there again I'm not sure every hospital needs an MRI, I don't think it does.... And I don't think every hospital in the world ought to be doing open heart surgery or brain surgery. And I don't think we should. We aren't. But I do think that we should be able to do every test that is necessary at the time. I don't like sending people away to get a test and come back in this area. It's irritating for them, it's irritating for me. I wish we had more of those type services available. But we don't, and we don't have unlimited resources at all. We do as well as we can with what we have and that's about it. (Dr. Waters)

Physicians also described how access to sophisticated services and to specialists was often *irrelevant* because many local residents could not afford such treatment.

Another constraint that we have is lack of finances. A large part of my practice are indigent and that, it's not necessarily the money for me, it's the money that is necessary to do testing, the money that's necessary to buy medication which is outrageously expensive in most cases especially those medications it seems that people have to have like cardiovascular drugs or chemotherapy drugs that are just beyond the finances of most normal middle class people.... Most coal mines have laid off all their workers so that the percentage of people that I have who don't have third party payors, insurance, are, is great too, and everything they do comes out of their pocket and for that reason you are, I feel, constrained not to do anything if I can get by without doing it, in terms of testing and things of that nature. (Dr. Waters)

The other difficulty I did not mention to you is really when you want to refer a patient, a patient, refer a patient. Referral to another doctor, you know a patient comes with chest pain and a sign of heart problems or lung problems or kidney problems and you want to see a, uh you just want a consultation, they

cannot go, they don't have money. It's just, I have to send them to Sikersville, 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 Sikersville 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. (Dr. Alloju)

Thus, while the doctors were socialized into a curing model that celebrated specialized, technology-based care, such care was often unavailable, sometimes unnecessary, and usually unaffordable. Instead, new diagnostic skills unbuttressed by technology had to be developed by the physicians.

*Practicing General Medicine.* A second problem was that the specialized nature of medical training did not prepare Fairmount County physicians for the broader range of skills needed for practicing in an impoverished community. Specifically, medical schools' primary focus on *acute care* ill prepared physicians for the practice of *general medicine*. For instance, Dr. Alloju lamented that he never encountered minor health issues during medical school and was forced to learn general practice skills on his own.

Uh, you know in your residency you don't do a lot of you know encounters with patients--it's just dealing with in-patients, with sick patients in the intensive care unit. And you are very good at it and then when you go and practice, the patient comes with minor issues, and you never saw it in your residency. You never saw minor issue, I don't know that to do, and you have to read and you have to learn. (Dr. Alloju)

The doctors were forced to rely on themselves to get the general practice training that medical school failed to provide. Yet they often felt isolated.

You know if you work in a small community where there are no big centers to rely on, where you have, you have to rely on yourself and, you know, a few people. (Dr. Sandoral)

Another concern is uh, with this area is so isolated, we are alone in here. We sort of feel lonely regarding our advancement of our medical knowledge. We have got no peers to discuss our cases, so we just have to go to the book and read. Then seminars, that's all. (Dr. Chavda)

They were even isolated from continuing education, which was unavailable or required significant travel time.

I think we need uh better continuing education available to rural areas. [R: Can you elaborate on that?] Well, we are now in what they call that superhighway or whatever. I think we should be able to pick up videoconferencing you know. It's not available in this area. Uh, if we have to go and take continuing education, we have to do that on our own. We have to go to Atlanta. Nashville. Or Charlottesville. But they are starting in this area now, piecemeal, starting regular continuing education classes you know. But it has been going on for only a few years. And it doesn't even meet the requirements of the American Association of Family Practice--50 hours a year. They give only maybe, maybe 10-12 hours a year, so you still have to go somewhere else. That's one of the constraints that we have here. (Dr. Sandoral)

Given the need for the skills of a general practitioner in rural medicine, the doctors lamented that the specialized structure of medical school does not yield enough family practitioners.

[We need providers who are] generalists, mmm family practitioner, mmm you need to have a good idea of all the specialties, uh pediatrics, surgery, uh cardiology. Uh like you can, uh you are able to treat uh relatively minor cases without sending them to the hospital. That's what we need in here. (Dr. Chavda)

At the time that I was there [in med school] there was no training whatsoever geared to enable people to work in this area, excuse me, or any other area of need like inner city ghettos, things of that nature. It was assumed that everybody there would work in a city atmosphere, in a specialty, and that's what the training was geared towards, there was no family practice training. (Dr. Waters)

The need for local physicians to serve multiple roles also supported the need for more generalists.

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. (Dr. Alloju)

Another concern expressed was that the health care system is not set up for preventive care--that the predominant emphasis on "incident treating" means not enough attention is given to preventive issues.

All the medical practitioners in this area are geared toward incident treating, rather than preventive care. And [this] is something that I have been interested in a long time, and I have done this sort of thing. Not often, because of the time involved, but disseminate information to people. If a document says for regular check ups, things of that nature, other than. 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. Most times, most of the people that we see is in crisis, or they're sick. (Dr. Waters)

Dr. Waters noted that nurse practitioners (in comparison to doctors) "are much better versed in prevention and much better versed in ordinary everyday health care."

These findings are consistent with charges of critics who have noted that medical school curricula are greatly out of sync with consumers' actual health care needs and the realities of today's marketplace. For example, about 75 percent of deaths in our country are from chronic disease, yet medical schools focus most heavily 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).

### **Curing Versus Caring**

The dominance of the curing orientation and its technical, specialized care fosters a disease-oriented or problem-oriented view of medical encounters. Yet Fairmount County physicians exhibited some elements of a caring orientation as well. For instance, Dr. Chavda noted that rural doctors are more oriented toward helping people than their peers in urban practice.

Comparing city doctors and rural doctors, it's just a matter of the, how would you say that, the personality of the doctor.... You know so it's more of a, mmmm, helping people. I would be much happier working in a big hospital, working with my peers, having more discussions with them. And in here it's too lonely. But uh, I felt the need in this area, that's the main reason I moved here.... I got this kind of personality, helping people. (Dr. Chavda)

He also noted rural doctors treat patients as more than just a number.

In big cities uh you are just like a number in there. A patient will get in and expect the doctor uh, uh to treat them, then they get out. In here, uh they can, they know you, it's a small community, everybody knows each other, uh they treat each other as friends. (Dr. Chavda)

He stated, "You should have compassion for the area, for the people" to practice rural medicine. Dr. Sandoral concurred and shared some examples of being compassionate.

Basically you know kindness is, kindness is good medicine, and being compassionate is a good medicine. And I'd really like uh, oh, I'll give you an example, you'll probably like an example. A patient came here and uh her mother died on the floor and the family was of course concerned about her you know. And so they came to the emergency room expecting that they would be given a shot for nerves. So when I talked to the patient I said, 'Well what's your problem?' And then she broke and cried and she said that her mother died. 'Well,' I said, 'I'm sorry that your mother died but uh maybe she's better off rather than suffering in this hospital or in this world.' So they uh asked me should she get a shot. I said, and I told her, 'What is the best medicine for somebody who lost someone?' And they just look at me and I said, 'The best medicine is for you to cry. And accept the fact that she's better off there than here.' And uh so the uh woman cried. And I said later on, 'Do you still need a shot?' She said, 'No I don't need a shot. I just need to cry.' (Dr. Sandoral)

I think we neglect the patients family a lot of times. That's a problem.... A lot of times we forget about the other people who are also suffering. This uh, the families are suffering out there not knowing what's happening to their mother and they only have one mother OK so I think in the hospital you know if someone can talk to the family while you know while someone is taking care of the sick person you know I think it helps with the healing process. Especially with the disruption of the family that might ensue because of if the patient dies you know there's a lot of trauma to the family. (Dr. Sandoral)

However, the doctors' notions of caring were fairly narrow. They felt compassion for their patients, but this compassion was restricted. That is, the physicians' manner of caring rested in an uneasy tension with the curing model in which they were trained and socialized.

In terms of what makes you [a doctor] feel good is if you really help somebody. And I have had a few patients, several patients that I have really helped.... We have people come into the hospital all the time with heart attacks. We have a medicine now called TPA, that we can give to them and abort a heart attack. You save somebody's life like that, you feel like you have done something very worthwhile.... Bad examples...the person who has, the first time you see them they've got uh metastatic cancer. You lost the ball game at that point. You can just be supportive, you can't really cure them. I've got one patient that we have been seeing for 8 or 10 years. We initially diagnosed her as having breast cancer. She had 7 or 8 children and her aim in life was to wait till they all got

through high school. I don't think she is going to make it because she is now kind of getting toward the end of the line. That's one's that are not very satisfying. [R: The person you talked about where you can be supportive but you really can't cure. How does that make you feel from the doctors point of view. How does that impact you.] Well, of course doctors, their goal in life is try to help people. So you feel like you have not succeeded in that case. But personally I take it very well. (Dr. Thomson)

In discussing what makes a good service encounter, this doctor shows caring impulses as well as a problem orientation (i.e., that a good service encounter is one in which he saves someone). Further, he discusses the dissatisfaction of having a cancer patient that he cannot cure and for whom he can only be supportive. This physician does not seem to recognize that being supportive can be helpful to a patient in and of itself.

*Problem Versus Consumer Orientation.* However, despite some presence of a caring orientation, the curing model dominated Fairmount County physicians' thinking and practice--the latter orientation is entrenched in the medical establishment. For example, consistent with a disease orientation, physicians tended to objectify consumers as diseases or as mere body parts--not as living, breathing human beings.

When you train in medical school, they train you to treat high blood pressure, diabetes, heart attacks. (Dr. Thomson)

When you say women's health, I guess that's what you're referring to mostly...reproductive type stuff. Pap smears, mammograms, ovaries and all that stuff. (Dr. Thomson)

Similarly, the doctors often viewed consumers only as problems to be fixed.

It's uh satisfying when you can, mmm diagnose and treat the mmm an illness which is uh, uh challenging. And I think that's the main uh, you know the happiness of a doctor, the challenge of solving the problem and being able to solve it. That makes everybody happy. (Dr. Chavda)

An illuminating aspect of this problem orientation, and further evidence of objectification, was the view of the service encounter as an intellectual exercise. For instance, Dr. Sandoral described patient interactions as an opportunity to exercise his training and knowledge of medicine and he lamented that limited resources forced him to "waste" some of his training.

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. (Dr. Sandoral)

This finding is consistent with Bloom's (1988) observation that medicine and medical education are primarily intellectual activities and that intellectual medicine takes precedence over goals of performance and professional behavior.

A detrimental consequence of this problem or disease orientation in isolation of the person is that health care is not addressed toward consumers as whole persons. Consumer needs and concerns that extend beyond the immediate medical problem (e.g., psychosocial issues) are largely neglected. The focus on "crisis" and ICU care result in a lack of attention to the whole person.

Some of the times we get so wrapped up in crises, because somebody is sick, ICU care, things of that nature. We really don't have time for, to get to know the people, as in people as, what they might need psychologically as well as physically. (Dr. Waters)

The disease orientation is amplified when physicians are burdened with unreasonable patient loads.

There aren't enough of us. It, to really do justice to taking care of somebody in all ways, preventive as well. Um, we're busy, all of us are busy. Dr. Thomson and I are extremely busy, and we have large practices, and it's hard if you're seeing 35, 40 patients a day to give each patient the amount of time they need to cover everything. (Dr. Waters)

This disease or problem orientation provides further evidence of objectification-- patients are not whole persons, they are merely diseases; physicians are trained to and sometimes forced to treat only diseases, not whole persons and their range of concerns. Recall that taking a caring, whole patient perspective means attending not only to a consumer's disease but to her experience of illness and social and emotional needs. A caring orientation focuses on healing the *person*, not just the disease.

*Blaming the Individual versus Blaming the Structure.* Consistent with the curing model, the physicians isolated the illness from the person. Moreover, physicians frequently held the women accountable for their health problems. For instance, providers attributed poor health outcomes to the women's inadequate education, ignorance regarding proper nutrition and healthy lifestyle habits, and failure to engage in preventive care or adequately use existing services.

I think it has something to do with education in addition to the reasons which I told you about earlier that people don't, does not come here to see the doctor unless they are very sick, unless very sick, so they, they don't you know come see the doctor for an annual physical exam or uh you know as I told you annual breast exam or pelvic exam or rectal exam even. And so uh that's uh you know one of the factors here--poor compliance uh on the part of the patient with the women. That advice is not uh just toward preventive issues, it is really even with therapeutic issues and treatment of diseases like you know I had a hard time you know convincing patients here and have them to really comply with taking their medications like you know their blood pressure medications. (Dr. Alloju)

Food, dieting habits. People here consume a lot of fat and, most of the time it's, they eat uh fried foods so they eat uh too much fat in their diet. (Dr. Bahrani)

People, especially women in this area, don't consider health care as part of their day to day activity. It's only if they get sick, if they feel ill, that they'd seek care. (Dr. Waters)

A lot of the, most of the thing that we battle, the worst thing that we battle here, or in any rural community, is people are not oriented, and this is, is women as well as men, women primarily, actually, are not oriented towards preventive care at all. They, for example, I'd say the percentage of people, of women in Fairmount County who have regular pap smears is probably twenty percent. Or mammograms that's, it's not high on their list of priorities. Um, often they find problems too late for that reason. (Dr. Waters)

One physician suggested that women do not even think about health care, and when they do, it is because of an external stimulus like seeing a health facility, not because of their own knowledge or internal motivation.

I think probably, you know a lot of patients here they, again they don't have money to go and see the doctors, and they don't think about it. And when they see the [Health] Wagon here just passing by or crossing by and they might, it just, it might stimulate their thinking about seeing a physician or asking for medical help. (Dr. Alloju)

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 the women's social context on their health and ability to get health care.

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?] Well, *I guess there is just some reluctance to go to the doctor.* I don't know how you feel about it, but most people, they would rather be home than be in a doctor's office. [R: What are your thoughts on why they are reluctant?] 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 doctors office and spending half the morning there. It's partly education, you know and just kind of making appointments and calling them if they don't come in. 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.* At least the ones that I am familiar with--there may be a lot out there that don't. So I am sure there are some of them that finances is a problem. Transportation you know some of the patients that I have, have trouble with transportation. .... Some people are just shy. *They don't want to go to the doctor unless they got a problem.* (Dr. Thomson, italics added)

This doctor believes that the decision to not see a doctor is "usually not financial" and that "most" people have some kind of insurance. Such a viewpoint illustrates that he does not fully understand the struggles of being an Appalachian woman trying to get her health care needs met in an impoverished and medically underserved community. Similarly, another physician blamed women for "not bothering" to get pap smears and mammograms, but failed to mention that such services are poorly available in Fairmount County and unaffordable for a great majority 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. (Dr. Waters)

This tendency to ascribe poor health status to individual characteristics and lifestyles and either ignore or downplay the contribution of structural factors has been referred to as "blaming the victim" (Ryan 1971; Wallack, Dorfman, Jernigan, and Themba 1993; Williams 1990). This theme is consistent with the culture of poverty thesis discussed earlier that blames Appalachian people's poverty on their own cultural inadequacy. Garvin's (1995)

research on health care in an Appalachian community provides further evidence of victim blaming.

While the physicians did sometimes recognize and identify structural barriers to health care access, they still placed the primary blame on the women. For example, one physician discounted the explanation of the poor availability of mammograms in exploring the underutilization of these services. Yet she still blamed the women for not using these "poorly available" services.

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. (Dr. Robertson)

In another example, the physician recognized that women sometimes cannot afford to buy prescriptions, but he still blamed them for poor compliance.

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 forget about it. He end 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. (Dr. Alloju)

Similarly, a doctor recognized that many of the women do not have adequate incomes to eat properly, but he still attributed poor eating habits to individual preferences.

I think people they, they don't eat properly because they don't have adequate income to buy whatever we tell them to buy. Like you tell them to buy lean milk...and they want hamburgers and hot dogs.... Fruits cost a lot more and it's easier for them to go buy a hot dog or a hamburger and eat that right away. (Dr. Bahrani)

*Education and Individual Behavior Change as the Solution.* Consistent with this tendency to blame the women for their problems, the physicians' most common solutions for

improving health care access and status were to get the women to change by educating them. If the women are responsible for their problems, then the burden rests on them to fix their problems.

The first place that I would start would be education. (Dr. Robertson)

I guess educational efforts would be the best thing [to improve health care]. Because we know what to do and can do it if we get them in here. But, you need to get them to come in. (Dr. Thomson)

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. (Dr. Chavda )

Educate these people, find a program, health program about lecture, giving lectures in these areas. And seminars. And have people come you know and invite people to come and hear about health issues and that should help a lot. (Dr. Alloju)

While physicians sometimes offered environmental or structural solutions to problems in health care delivery, their foremost recommendations still focused on how the *women must change*.

Better health care is uh, main thing is more emphasis would be put on education. Mmmm, the second is improve the financial aspect in their life. Cause without education and without their finances, even if they, even if they want to be treated they can't go. Those are the main things. (Dr. Chavda)

A major problem with this individual behavior approach to improving health care is that it puts the burden of improving health status on individuals and largely ignores the role and responsibility of social institutions, such as the medical establishment, in improving health. For instance, in the following quote, the doctor assumes that getting more women to go to the doctor is the solution, thus effectively ignoring structural barriers to health care access such as money, insurance, and transportation.

Well, we could do a better job of getting people in for pap smears and mammograms.... We thought about sending out little mailers, but I don't know. We may do that sometimes. That is something that we could do to try to promote that. Like if somebody's pap smear is due, like next month, well this month send them a post card saying your pap smear is due. That would be a good idea. (Dr. Thomson)

A primary implication of the curing model is that it isolates the disease from the person and her social context. Further, in the curing model, the star player in the service encounter is not the consumer but the doctor.

### **The Service Encounter: The Power of the Physician and One-Way Communication**

The United States health care system is a model of professional dominance and physicians reign supreme (e.g., Aries and Kennedy 1986; Cockerham 1995; Conrad and Schneider 1986; Freidson 1970). The entire health care industry, ranging from patient care to research to administration, is subordinate to doctors' professional authority (Cockerham 1995). This state of affairs has persisted since the prehistoric ages when medical practice originated in magic and was viewed as a priestly art (Sidel and Sidel 1986). Part of physicians' influence lies in their power to define what does and does not constitute disease. "The medical profession has first claim to jurisdiction over the label illness and *anything* to which it may be attached, irrespective of its capacity to deal with it effectively" (Freidson 1970, p. 251). For example, when pediatricians were faced with declining numbers of children to treat because of improved living conditions, public health measures, and vaccinations, they expanded their professional domain to include children's behavioral problems (Pawluch 1986). The new "behavioral pediatrics" consequently led to the medicalization of numerous childhood problems (e.g., Conrad 1975). Similarly, the authority to determine *how* to treat disease gives physicians wide-ranging powers. Medical licenses give doctors an exclusive state-supported right to practice medicine, giving them legal rights to do what others cannot, including cutting the human body and prescribing drugs (Conrad and Kern 1986).<sup>35</sup>

*The Power of the Physician.* Consistent with the "commander-in-chief" status accorded physicians in our health care system, Fairmount County physicians did indeed view themselves in power and in control. First, they viewed themselves, not consumers, as the primary "monitor" of health and thus largely ignored the women's role in the management of their own 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, I call the monitor of your health. (Dr. Sandoral)

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<sup>35</sup>Physician dominance extends well beyond the immediate domain of treating patients, however. For example, in defining what medical services are or are not necessary, physicians directly impact the number, types, and work tasks of health care laborers (Aries and Kennedy 1986) and the purchase and utilization of equipment.

Like you have to come to the doctor to, even when, when you're not sick, just for the maintenance of your health situation. (Dr. Alloju)

Second, the physicians viewed themselves as having the power to help patients who look up to them.

The best [encounters], I think the best 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. (Dr. Sandoral)

We can communicate easy with people here 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.* OK. Very simple, very kind, very loving, and they appreciate a lot. (Dr. Alloju, italics added)

The good things [about working in this area], you will find that it's, that it's not as stressful as other areas. You will find it easy to work there. You'll find that people really appreciate what you do for them. You find that people here in general, not just the patients, are very kind, and you, they will respect you a lot as a physician here. (Dr. Alloju)

Third, this power is also found in the physician's ability to control the service encounter during the traditional clinical interview (Kleinman 1988, 1986, 1980; Waitzkin 1991). The physician controls the domain and flow of what is discussed.

Uh what I learned [in medical school] is that you should be orderly you know in interviewing a patient, you know you just don't jump from one place to another you know. When you, you have your thinking and logically uh establish for, or a question establish or follow a sequence you know it is easier for you to practice medicine [R: And what is the sequence of the medical interview?] Well, chief complaint. Is there a present illness you know. Past medical history. Social history...family history is very important. Physical examination.... Finally your impression or diagnosis. (Dr. Sandoral)

Talk to the patient and try to find out their problem. And diagnosis. And treatment.... There is a kind of recipe for [medical interviews]...they call it the soap method. S-O-A-P. Subjective--patient tells you what their problems

are.... Objective is just your examination. Assessment--diagnosis, what you think the problem is. Plan is what you are going to do about it. Are you going to just give them some medication, order some test, or what? So that's called the SOAP method. So that is kind of a way of kind of handling things in the office. (Dr. Thomson)

While consumers may approach physicians for multiple reasons, the physician's primary objective in a medical service encounter is much more narrowly defined--to make a diagnosis (Allman, Yoels, and Clair 1993). This primary objective dominates the service encounter--doctors obtain only enough information from the patient to facilitate diagnosis, often ignoring other important information.

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. (Dr. Thomson)

Existing research suggests that in forming a diagnosis, physicians generally use the first thing mentioned by the consumer in describing the chief complaint, even though the most important problem may not be mentioned until later (Beckman and Frankel 1984).

Not only does the traditional clinical interview limit the domain of what is discussed, but it also limits the participation of the patient. Doctors control when and how patients participate in the service encounter.

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. (Dr. Thomson)

Most of the time the first part of *my encounter* [italics added] is the patient only--telling me. And that I try to give them as much time as they need to do that. A lot of people come in and say, 'I've got a sore throat,' and you have to do those, period. And that's OK. Then you say, 'Do you have fever, do you have chills? Does somebody else in the family have it?' That sort of thing. But if, if it's a more complicated problem than that and you listen, they'll tell you. That's the first part. The second part is, is examination--there's not a whole lot of anybody talking. The third part is primarily me talking to them. And telling them what I think they should do, what kind of medication I'm gonna give, what subjects to do them, and possible side effects, and got to be careful and that sort of thing. (Dr. Waters)

The physician's role in the service encounter is primary; the patient's role is secondary.

*One-Way Communication.* One implication of the physician-dominated nature of the medical interview is that it results in a one-way service encounter. That is, doctors ask the questions, control what information is discussed, and tell patients what to do. Thus the medical service encounter is a monologue, not a dialogue. This monologue form of communication is best exemplified in how patient education is viewed within the encounter. That is, to Fairmount County doctors, patient education consists merely of the doctor providing information for the patient-- "telling" patients what to do or "telling" them about health matters such as preventive care.

[We need] more emphasis on preventive care and more education, more general education...just flat telling people, educating people that this is needed and that there's problems that can be cured if you catch them early that can't be cured if you don't, that sort of thing. (Dr. Waters)

Educational efforts would be the best thing [to improve women's health]. Have your annual check ups, if you have any problem with bowel function or something like that to see your doctor. (Dr. Thomson)

Distributing brochures was another instance of this one-way transference of information from the expert to the novice.

And we have been very active in educating them, giving them pamphlets.... [We] do more on, emphasize more on preventive medicine. So, every female that comes in now we have a uh protocol to follow. We ask when they had their last uh pap smear. When they had their last mammogram. Mainly uh, uh, what do they call that? Risk factors they have. So we are emphasizing on those now in females. And because of that we were able to catch uh early cancer of the cervix. And uh cancer of the breast. (Dr. Chavda)

The doctors assumed that consumers will learn from this one-way educational method, and ultimately, change their attitudes and/or behavior.

Uh, a lot of times uh female does not voluntarily ask for the regular female examinations. You have to suggest that to them, educate them. The best treatment for, best treatment of cancer is early detection. *So we tell uh educate them about self-examinations of the breast, periodic pap smear, pelvic exam, mammogram. Then when they come to understand about it, they will submit themselves for breast examination.* (Dr. Chavda, italics added)

I think patients are intelligent--*if you explain to them, they understand you* know. (Dr. Sandoral, italics added)

This one-way perspective on patient education exemplifies what Brazilian educator Paulo Freire calls the "banking concept of education" (Freire 1970/1986). In this view of education, knowledge is bestowed by the knowledgeable (the subject--the teacher) upon "those whom they consider to know nothing" (the objects--the students) (p. 58).

Narration (with the teacher as narrator) leads the students to memorize mechanically the narrated content. Worse yet, it turns them into 'containers,' into 'receptacles' to be 'filled' by the teacher. The more completely he [sic] fills the receptacles, the better a teacher he [sic] is. The more meekly the receptacles permit themselves to be filled, the better students they are.

Education thus becomes an act of depositing, in which the students are the depositories and the teacher is the depositor. Instead of communicating, the teacher issues communiques and makes deposits which the students patiently receive, memorize, and repeat. This is the "banking" concept of education, in which the scope of action allowed to the students extends only as far as receiving, filing, and storing the deposits (p. 58).

The banking concept not only ignores the agency and creative power of students, but maintains the status quo. By presenting the world as static and unmoving, this educational method serves as a form of oppression by prohibiting students from developing the critical consciousness to intervene and transform the world.

Consistent with Freire's (1970/1986) banking concept of education, Fairmount County physicians viewed themselves as the experts whose job was to deposit their knowledge into the receptacles of the unknowledgeable women. This practice served to restrict the women's action. The women were forced into a role as passive objects, as mere depositories of information. The good patient was the submissive patient who "comes in and tells you openly their problem and submits to the examinations and the tests that you suggest to them" (Dr. Chavda). Thus the physicians' control of the service encounter rarely if ever allowed the women to escape this role.

This chapter has shown how the dominant curing paradigm of the medical establishment is reflected in health care delivery in Fairmount County. Not only is the disease orientation manifest in the structures and practices of our medical system (e.g., technology-based, specialized training; curing orientation), but it is also manifest in the service encounter, a one-way encounter in which the physician reigns supreme, the consumer is a mere depository of information, and the underlying social context of the consumer is often ignored.

## **CHAPTER FIVE**

### **THE VOICES OF THE WOMEN**

Obtaining health care was an ongoing struggle for Fairmount County women. As discussed in Chapter 3, economic and environmental conditions, community obstacles to healthy behaviors, and maldistribution of providers and services all served as risks of poor health and barriers to health care access. Nevertheless, the women encountered difficulties even when services were available. Their stories highlight institutional procedures and practices that differentially impact who gains access to those services and physicians that are available. Once the women are within the medical service encounter, they described a variety of distancing behaviors employed by the doctors and how these behaviors contribute to a dehumanizing health care encounter. The service encounter was cold, distant, and often humiliating. The women's needs and concerns were rarely met. The women linked problems in health care delivery to structural barriers to health care access and to dehumanizing treatment in the service encounter. These views stood in sharp contrast to the doctors who attributed limited health care access and poor health outcomes largely to individual behaviors.

The first two parts of this chapter explore the difficulties the women experienced in obtaining health care, both obstacles in accessing the system and problems within the service encounter. These two sections illustrate that the health care system did not meet the women's needs. Consequently, many of them opted out of or minimized their use of the health care system. The third part of this chapter explores the strategies the women took on their own to actively manage their health needs in light of these difficulties. These health management activities took place both within and outside the formal health care system.

#### **Barriers to Health Care Access**

Equity in the distribution of health care services is a serious problem in our health care system. The United States health care industry is characterized by a two-tiered distribution system based on ability to pay--a private tier that predominantly serves higher income groups, and a public tier that serves a majority of lower income groups. In contrast to the private tier, the public tier is a system of welfare medicine supported by public health insurance and characterized by lower quality of care, longer amounts of time in waiting rooms, and more bureaucracy (Cockerham 1995). Aday (1993) lists some very telling examples of how many institutional doors are closed to vulnerable populations, particularly those who lack the resources to pay for services.

Almost three out of ten obstetrics providers refuse to see women on Medicaid. Diagnosis related group (DRG-) based reimbursement under Medicare has

encouraged some providers to discharge chronically ill elderly patients in less than stable condition. Private insurers have increasingly sought to exclude certain high-risk groups, such as persons with AIDS, from coverage, or to limit the benefits of others (those with mental health or substance abuse problems, for example) (Aday 1993, p. 181).

Further, following treatment, public tier clients are more likely to return to living conditions that put them at further risk for poor health (Cockerham 1995).

This state of affairs means that economic disadvantage often translates into medical disadvantage. Considering the 37 million Americans that have no insurance and another 22 million that lack adequate coverage (White House Domestic Policy Council 1993), this situation is alarming. Of course, Fairmount County women interviewed in this study experienced the public tier of the health care system.

First, cost-related barriers to access are discussed. Health care costs are interpreted broadly to include actual charges and methods of payment as well as time, energy, and frustration. Second, procedural barriers to access are discussed. Specifically, accessing health care services depended on whether one had insurance or not and consumers received differential treatment based on their paying status (e.g., private pay, Medicaid, no insurance, no money).

### **Cost-Related Barriers**

One of the greatest obstacles to health care access was prohibitive costs.

Like my heart pills ... one prescription, of course, is from 80 to 120 dollars. Ain't no way anybody can get that. (Interview with JoAnn)

Like my mother-in-law, she don't have any insurance. I know that she is of the age where she needs yearly mammograms and stuff like that. She don't have them because she can't afford them. And she says if she did have them and something was wrong she wouldn't have the money to take care of it so she would rather not know if anything was wrong or not. (Interview with Elaine)

The lack of payment options was also problematic. Some of the women could afford small payments spread over time, but this option was rarely available.

Well, it's like a child's physical right over there at the clinic...\$80 for one child's physical...Outrageous. And I mean there ain't none of this 'I'll pay so much a month.' They got to have the \$80 right then and there. (Focus Group 2)

I'm 43 years old and I've never had a breast exam.... You can't afford to go get one. I mean it's nothing that's here that offers you like, say come to the Health Department, or, come and we'll do 'em for maybe ten dollars, or we'll do 'em free, or we'll go by the pay scale. (Focus Group 1)

It used to be that the hospital would take you in. But now if you don't have money, they don't take you in. (Interview with Martha)

Martha also indicated that no payment plans were available at the hospital.

A common theme was that even when women were able to scrape up enough money for an office visit or make some sort of payment arrangements, they could not afford necessary tests, medication, or follow-up visits.

Sometimes I might have, like the office call a lot of times is \$27.... Then sometimes if I can't then they will let me charge. But then the medication is what the big problem is. You've got a \$27 medical bill, that's just straight out seeing a doctor without any blood test, blood work, any lab or x-rays or anything like that. But then you go to the pharmacy.... And my medicine, if I do get my medicine filled for the month, it's \$230 some dollars. So some months I have to do without medication. And so I have been known to do without my blood pressure pills and my fluid pill. (Interview with Paula)

The high costs of health care combined with the women's economic circumstances (e.g., lack of money and/or health insurance) frequently meant doing without needed care.

In addition to access barriers related to financial costs, health care costs included the time, frustration, and hassle of getting care. Informants experienced extremely long waits in getting appointments.

When we called to get you a pap test over there ... at the Health Department, it was four months before she could get an appointment. I said forget it. Four months to wait to get one pap test. (Focus Group 2)

I been here three months and I've been trying to get an appointment to get the Norplants to keep me from getting pregnant. And they just, they just keep black balling me. (Focus Group 2)

One woman described how one of her friends got entangled in bureaucracy at the local health department which delayed her ability to obtain birth control by many months.

Sixteen months through the Health Department. Shoot, she's even went over and had pap tests. You know they say 'Well you have to come in and have a

pap test.' She come in and have the pap test: 'Well in three months we'll try to give you your Norplant.' Well, she'd go back in her three months, 'Well the nurse is not here today, you'll have to come back next month.' And the next month, 'Well we can't do it this time.' You know, I mean there's something all, all the time, they don't want to do... (Focus Group 2)

Similarly, long waiting times at the health department, social services department, and doctors' offices were commonplace, even for scheduled appointments.

Well, the public health clinic, everybody gets a 9:00 appointment and be over there til it's time for it to close. Don't go. (Focus Group 1)

You would go there [doctor's office] and a lot of times you would sit there all day for that appointment. You might have one at 8:30 and you might get in there at 3:00 this evening. (Interview with Helen)

But in addition to the demands placed on the women's time, getting care was emotionally taxing. Obtaining health care was often frustrating.

Last month I had to take Susan over there [Social Services]. My appointment was at 9:00 to go in have them do, check her blood, ah, give her WIC vouchers. I was there from 9:00 til 3:30, because they, one calls you in, you go back and sit, they call fifteen, twenty people in all the way around, then start giving you your things. I mean these kids they get hungry, they get tired, they don't want to sit. (Focus Group 2)

There is not room [in the waiting area] to even sit for even a little three foot high kid to even sit! And these people are all ahead of me. [We finally got in] four and a half hours later. With a 6-year old! ... No kid, especially a 6-year old, should have to wait [so long]. (Interview with Rhonda)

Some authors have noted that waiting reinforces the power of the provider and the subordinate status of the consumer. "To be kept waiting is to acknowledge that one's time and social worth are less valuable than those of the person who imposes the wait" (Fitzsimmons and Sullivan 1982). This enforced waiting is consistent with the physician's position of power, authority, and status within the medical establishment, which was discussed in the previous chapter. Further, waiting is exacerbated for those relegated to the public (vs. private) tier of our health care system (Cockerham 1995).

## **Procedural Barriers**

Health care access depended on whether one had medical insurance. Many women told stories about doctors and institutions that delayed care or refused to see them if they did not have some form of insurance.

When I had [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 I have them people who they knew had insurance who were admitted immediately. (Interview with Fran)

They let me stay in the emergency room seven and one half hours laying there. They had not offered to send me upstairs. They kept worrying about who was going to sign the bill. No insurance. (Interview with JoAnn)

Most hospitals ... if you don't have the proper insurance, you got that against you before you even go in the hospital door. (Interview with Paula)

Thus adequate health care was compromised when medical workers spent so much time worrying about how the organization was going to be paid.

Further, the women experienced differential treatment based on their paying status. Differential treatment was manifest in four ways. First, the women experienced longer waits.

And then sometimes you wait for hours and you don't get called because somebody else comes in with insurance or money and they're in, they're in there just like that. (Focus Group 1)

Second, when they finally saw a doctor, the contact was brief.

I also seen a lot of, you know, if you didn't have insurance, you was in and out, as opposed to [those with the means to pay]. You know it was kind of quick. (Interview with Kathy)

Doctors here have realized that if you are a Medicaid person, it's time--in, out, least amount, least path of resistance, shall we say so to speak. You know what I mean? Minimum care, most people you can see in a day. (Interview with Rhonda)

Third, without the ability to pay, patients received care that did not include expensive tests and procedures.

I was there [doctor's office] with chest pain and my blood pressure was up, I was having chest pain, cause he [the doctor] said, 'Well you need a EKG.' And he said, 'Do you still have your, ah, card?' And I said, 'No, you know my husband lost his job and don't have no [insurance].' [The doctor said 'Well I don't think you need one [EKG].']

I was sick as sick could be...and they was too scared to even do like EKG on me because I didn't have insurance. After he found out I didn't have insurance, well you don't need the test. So that's something to worry about. Well if I had the insurance well I needed the test. But after I didn't have the insurance I didn't need the test. You know, and it, it's just a, it's just a cycle all the time. (Focus Group 1)

Fourth, the differential care was manifest in the attitudes and treatment of patients. The women felt that they were treated with little respect because of the stigma of having no insurance or being on Medicaid.

To me I think they treat people differently if they have Medicaid or something like that. I think they do, yeah. [R: Can you give me an example.] Well, they don't say anything, but you can tell, their expression or their attitude or something like that. They think they're giving it away, but it's the government giving it away.... Like I said, if you are on government insurance, like you know Medicaid or something that, they do treat you bad. If you don't have insurance, they treat you bad. (Interview with Martha)

[What we need is] just for the doctors and nurses, health care professionals, to make it more individualized.... [R: Can you explain what you mean by that, more individualized?] Well, that goes with, you get the momma that comes in that's got the little boy that is on Medicaid. Not to treat her like she was a financial burden on the state cause her child is sick and needs to be seen by the doctor. and, you know, 'welfare case.' Um need to treat them like a concerned parent. It's hard, I know working, when I worked in pediatrics, when we would see the mothers that wouldn't get up and take care of the children and it would really get aggravating if the baby laid there and cried and just wanted to be held by its momma. And then not, I don't think that people, upper class or society or whatever, I don't think that they should be not taken care of because they are upper class. But I don't feel like they should be made to feel any more special. Because a sick child is a sick child. A sick momma is a sick momma. It don't matter whose paying it or how it's being paid. If they're sick they need to be took care of. And I think it needs to, that's what I mean by

individualized. They don't need to put people in certain categories, you know. Just take them as they are and take them as they come. Take care of them. That's what I mean by individualized. (Interview with Kathy)

Thus the women encountered numerous cost-related and procedural obstacles that served as barriers to access. All of these obstacles limited informants' health care access. In the next section, problems within the service encounter are explored.

### **The Service Encounter**

Services marketing research affirms the importance of the human interaction component of service delivery. The service encounter, defined as that moment of interaction between the service provider and consumer, can affect customer satisfaction, perceptions of service quality, and future purchase intentions (Bitner 1990; Bitner, Booms, and Mohr 1994; Bitner, Booms, and Tetreault 1990; Crosby, Evans, and Cowles 1990; Crosby and Stephens 1987; Surprenant and Solomon 1987). Research specific to health care contexts also supports the importance of the human interaction element in consumers' service evaluations (e.g., Brown and Swartz 1989; John 1991). For example, many of consumers' desired physician qualities presented by Roth (1994) deal with doctors' interpersonal skills: personable (friendly, warm, caring, familiar with patient), communicative (open, clear), available (easy to reach, willing to listen, not preoccupied), and respectful of patients (treats as equal, confidential, honest and candid). Both the research on service encounters and service quality recognizes the central role of these interpersonal dimensions. For instance, three of the dimensions of service quality--responsiveness, assurance, and empathy--are directly related to the human element of service provision (Parasuraman, Zeithaml, and Berry 1985, 1988).

A common expectation for good service delivery is that the provider has a consumer orientation in which he or she is attuned to consumer needs. Nevertheless, the experiences of the women in this study stood in marked contrast to these normative descriptions of good service encounters. Rather than being consumer-oriented, area providers were perceived by the women to be distant, inattentive, and unconcerned. A common theme across dissatisfying service encounters was the use of distancing behaviors by providers. Social distance is defined as the use of techniques to reinforce the inferiority of subordinate groups (LaPointe 1992). The providers' distancing behaviors can be grouped into three general categories: minimizing time, minimizing contact, and minimizing the person. These behaviors are explored in the next three sections.

#### **Minimizing Time**

Providers' minimizing time was a common distancing technique experienced by the women. Rushing the service encounter was the most typical manifestation of this practice.

Like they're always in a rush, you know, your two minutes are up, get out of here, we got somebody else coming in. (Focus Group 1)

Lot of them [doctors] always seems to be in a hurry. (Interview with Rita)

They just doctor you, give you medicine, and send you out the door. They don't take time. (Interview with Elaine)

All that they're [doctors and nurses] after is get 'em in there and get 'em out. You cannot take 80 patients through one office a day and know what's wrong with them. You can't. (Focus Group 2)

Another way that physicians minimized time with clients during service encounters was by taking diagnostic short-cuts. One short-cut was the common practice of jumping to a quick diagnosis without conducting a thorough exam or giving women time to explain their problems.

When you go in he [the doctor] just start writing your prescription you know, and he don't take the time or anything like that with you. (Interview with Martha)

They [physicians] will not really examine you. They tend not to... 'Well, ah what's, what's the problem?' They'll write before you, you know really, you know right then you're trying to explain it, say your back hurt, what it is you know. They're not gonna come and try to give you a thorough exam--you know what spot, or what area, or nothing like that.... Sometimes, like I said, you just go and they just leave it to you, as to what is wrong with you and so they write down, we'll write out something for you. (Focus Group 1)

He [my dad] goes to Dr. \_\_\_\_\_ and he is having chest pains. Dr. \_\_\_\_\_ says 'We will do an EKG.' Hooks him up on the EKG right there in the office, reads the EKG. Now this man has been a medical doctor as long as time has stood. You know this is the instant diagnosis man, same one. Anyway, he looks at my dad, looks at the EKG and says, 'It's your lungs. Get used to it. Ain't nothing I can do.' Now bear in mind that Daddy has had black lung for what 15 years it's been. You know but this is unlike any black lung pains he's ever had, so he knew there was something else. He made it to the house and he could hardly stand up. We took him in the car to [the hospital] where they immediately admitted him cause he was having a major heart attack. He was in the hospital there for 3 days. I would like to know the number of people that Jack Kervorkian over there has killed. In plain English. (Interview with Rhonda)

Oftentimes a doctor's rush to formulate a diagnosis and propose a treatment plan meant that patients had to return later because the treatment did not work. This "trial and error" method of treatment represents another type of shortcut and was a frequent theme in the women's stories. That is, rather than taking time during the initial examination to thoroughly examine a client and formulate the most appropriate diagnosis and treatment, doctors tried out treatments and told women just to come back if they did not work.

[The doctor said] we'll write out something for you and take this and this should make you feel better and if it doesn't then you call me, or you come back in. (Focus Group 1)

I have had a lot of problems out of them [kidneys]. And the doctor that I would see, I mean like from July to October, every time I would go in to see him, I would have kidney infection and he would say, 'Take this medicine and come back in two weeks. And being if it's not cleared up, I would probably send you to a specialist.' It kept going and kept going until October. And then he finally did send me to a specialist. (Interview with Mary Ann)

[Why bother to] take them [your child] over here to the emergency room? And more than likely they'll just say 'Oh they've just got bronchitis, let's give 'em a pill, if this doesn't help in three days take 'em back to the doctor.' Well, then you owe them 250 dollar at the least. (Focus Group 2)

Relying on diagnostic "catch-alls" was another common way providers minimized time in service encounters. That is, frequently a physician's "quick" diagnosis was based on the stereotypical assumption that area women were prone to mental health problems of stress, depression, or "nerves" that could be solved by prescribing tranquilizers such as Prozac, Valium, or Lithium. One woman described how she was "going through the change" and her doctor ignored and trivialized her experience by attributing it to stress.

But when you tell, talk a doctor [about going through menopause] 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)

Depression was another diagnostic catch-all.

Another thing here, is the doctors. You can be sick, you can go in and tell them, 'I feel this way, and this way, this way.' And they'll say, 'Well we really think you're depressed.' And you know that's what it's coming from. 'We really don't think nothing's wrong with you, you're just depressed.' (Focus Group 2)

Having a health problem attributed to depression or to "nerves" was a common experience for the women, so much so that one informant said, "Around here...the number one cure--a nerve pill.... A nerve pill will cure anybody around here listening to these doctors tell it" (Focus Group 2). Helen suggested in our interview that the reason so many people in the community are on nerve pills is because doctors are too quick to prescribe them without evaluating other possible alternatives.

This finding that physicians used the assumption that local women were prone to mental health problems in order to shorten medical encounters and arrive at a diagnosis is consistent with some of the research on stereotyping. In an attempt to simplify the multitude of information available in social situations, particularly when one is motivated to make a quick decision, individuals assign persons to stereotyped-based categories for which numerous assumptions are already available (Jamieson and Zann 1989; Jones 1982). Further, some research evidence shows that people who stereotype are apt to find confirmation for such assumptions (Jones 1982). Allman, Yoels, and Clair (1993) propose that greater disparities between doctors' and patients' socioeconomic status will result in greater propensity for doctors to engage in stereotypical thinking when forming diagnoses.

Some of the most extreme cases of minimizing time made the women feel that providers were avoiding them and reflected a GROP ("get rid of patients") perspective (Mizrahi 1986).

Honey, they'll put you on anything that'll get you out of their office. (Focus Group 2)

The whole time you was [in with the doctor], they was patting you on the back and pushing you toward the door. (Interview with Kathy)

Well I guess if you've got insurance or Medicaid card they do, they try to help you. But, if you haven't got nothing, 'die or get out of my way,' you know. (Focus Group 2)

In summary, providers distanced themselves from the women by minimizing time with them through such practices as rushing the encounter, jumping to a quick diagnosis in lieu of thorough examination, using trial and error diagnostic techniques, and relying on diagnostic catch-alls such as "nerves" based on stereotypical assumptions regarding area women's mental health.

### **Minimizing Contact**

A second way that providers distanced themselves from the women during service encounters was by minimizing contact. This distancing was done by minimizing both talk and

touch, behaviors which are explored in this section. For example, the women described how providers frequently failed to explain things.

You go to a doctor now, and it's just in and out, in and out. You know. Cause they've got so many patients, they don't take time between patients to sit down and explain things to them. (Interview with Helen)

And when I found out I had diabetes, that made me really mad because they didn't explain anything to me. All they told me was to take my medicine, and stay away from sugar. They didn't exactly give me the diet that I was supposed to be on you know or explain anything and I had to order books and read books to find out exactly what it is I'm supposed to do and know the complications if I don't do what I am supposed to do. That bothered me a lot.... And I had so many questions and no answers.... [They need to take] the time to explain things to me because it makes me so mad that I have to spend all of my time researching what's wrong with me and figuring out what it is I need to do. I think diabetes is a serious disease and they should explain things more clearly to people.... He [the doctor] never listens, I don't think. I mean you know he'll listen to your symptoms, but if you got detailed questions or something you want to ask him, he just kinds of runs out on you know. Sometimes he don't even say what's wrong with you, he'll just go and have the nurse come back and give you a shot or give you your medicine and you don't really know what, what it is that's wrong with you. And I don't like that. Like one time my little boy had a really bad cough you know. He could hardly breathe. And I took him in, he gave him a shot and some medicine and he gave him some kind of breathing medicine and I didn't know what was wrong. And I had to stop him in the hall and ask him 'Why did you give him this? What is wrong with him?' (Interview with Elaine)

Thus the women often had to seek out information elsewhere because they did not get adequate information during the service encounter. Further, physicians often resisted requests for further explanation.

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 ask the pharmacy what was this medicine for. (Focus Group 1)

For example, sometimes such resistance stemmed from the doctor not wanting his authority to be questioned.

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.' [Instead of] explaining.... Well, that would make me so mad because there as 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)

Use of technical words was another barrier to understanding doctors' explanations.

That's the reason why I take care of myself. Cause the only thing they [doctors] do is tell you big words that you can't [understand]. That you don't know what they are talking about. And then, to me, they get very upset when you question them. And I like to know what they are giving me medicine for, if I get that sick where I don't have to go to the doctor. (Interview with Fran)

[Providers should] talk to these people and let them know, you know, don't blow in and say well, 'We'll go to do a colonization because you have got such and such wrong with your fallopian tubes.' Well you know, some people is like 'A what?' Well them big words scare. And I mean they scare bad.... If you've got somebody that don't understand what's going on, or don't understand them big ten dollar medical words, you need a doctor that can get down on their level. And a lot of doctors in this area depend on nurses to do that. (Interview with Kathy)

Closely related to providers' paucity of explanations was their common tendency to provide very little to no information to the women. One informant attributed this practice to physicians' stereotypical views of Appalachian people as uneducated.

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. Most of the people that I talk to here, just normal every day people, don't even know what their diagnosis was. (Interview with Rhonda)

Another informant described going in for numerous tests and never receiving a thorough explanation of the results. In fact, the doctor's response was cursory, almost patronizing:

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)

This woman's treatment led her to infer that the doctor thought she was not intelligent enough to understand the test results. Other informants told stories of doctors withholding important information.

Or it's like a doctor that does your pap tests for two, three years and knows you've got abnormal cells. Doesn't say anything until it turns into cancer, then when you're 25, 26 years old and have to have a hysterectomy. You know, you're wanting more children, you're expecting, you know, different things. And that doctor says, 'well it wasn't bad enough to say anything.' I mean abnormal cells are bad enough to say 'You got abnormal cells, we need to do something about it.' (Focus Group 2)

And she had this lump in her breast for the last two years where she had been going and they had not told her. And she got her old mammograms [sic] out and was looking at 'em and she found the lump that had been there for two years and they hadn't told her. Because the arrows was pointin' to it. And they didn't even tell her she had it. And now, it's big enough she can feel it. So she's probably had it for two years. And now, she's scared to death that it's cancer. (Focus Group 5)

This theme of minimizing communication is consistent with the view that the physicians see the service encounter as a one-way provision of information--a monologue, not a dialogue. Rhonda shared how she took her son to see a doctor for his asthma and the doctor made a quick diagnosis without examining her son *or listening to her describe her son's allergies*. He dismissed her comments with "No, this'll be fine, this'll be fine" and was persistent in his diagnosis without considering her input to the encounter.

[The doctor] took one look at [my son] and hadn't even listened to his lungs and goes, 'Mmm, boy's got asthma.' And started writing a prescription.... He wrote him a prescription as I was trying to tell him what he was allergic to, cause he had medical reactions before. And he said, 'No this'll be fine, this'll

be fine.' Now bear in mind, we live about 35 minutes from the closest hospital and about an hour from the closest good hospital. And so he gave him the medicine, we went home, my son reacted terribly to the medicine, he was very much allergic to it, it was a form of penicillin, which I had told him he was allergic to. Yes, yes. And, what, but he was so deadset. What bothered me more than the medicine, and that did bother me, was the fact that he was so adamant in his diagnosis, immediately upon entering the room what was wrong with my son. Without even doing anything. Just looked at him. (Interview with Rhonda)

These findings, that the physicians gave limited explanation and information provision, are consistent with other research that has found that people with lower class positions and educational levels receive less information from doctors (e.g., Waitzkin 1985, 1991) and are more likely to have their questions ignored (Ross and Duff 1982). In this study, however, receiving limited explanation and information reflected only one method for minimizing contact that the women experienced during medical service encounters. Sometimes providers minimized contact by not talking to them *at all*:

Every time you get a man doctor and get a pap smear you feel uncomfortable, you tense up, they never talk to you, they just go in there and snap it and bring it out and that's it, and you hear from 'em later. (Focus Group 1)

Failure to touch the consumer was perhaps one of the most upsetting distancing techniques that providers used to minimize contact. On one level, failure to touch communicated to the women that providers were avoiding them.

He don't even touch you for one thing. He look in your ears, and then your nose and he'll write you a prescription. (Interview with Fran)

Sometimes they act like they're afraid to touch you.... You know, and a lot of times they are very, sometimes I feel like stand-offish, maybe... 'What's wrong with you? And I'm gonna, you know, I'm gonna look at you.' You, you can't always explain, you know sometimes you may have to move around and touch a person, sometimes I've found them to be a little apprehensive that, they like, not touch you. You know like, just contact. (Focus Group 1)

However, on a deeper level, lack of touch sometimes conveyed to the women that they were dirty. Martha described a doctor's visit on which she accompanied her daughter, Kelly, and how the physician not only avoided touching Kelly, but instructed her not to get on the examining table--he made her stand:

When Kelly had her first baby I went to Dr. \_\_\_\_\_, cause I knew she was in labor like that. He made me feel like I was nothing but dirt. Because you know she was in labor and he was telling her 'Don't you lay on that bed' [and telling me 'Get her up from here.' I tell you I'll never forget that. And that makes a person feel like they're worth nothing. Cause I didn't have no money at the time. I didn't have any insurance and things. (Interview with Martha)

Similarly, many women described that they felt worthless during provider interactions. In the next section, these feelings are explored.

### **Minimizing the Person**

The way women were treated during service encounters often diminished their sense of individual worth. One distancing behavior the women experienced was when providers ignored their feelings, individuality, and unique needs and concerns. Physicians were often described as cold, uncaring, and dispassionate, oblivious to the intense feelings that arose in the health care encounter.

The doctor and nurse walked over in the corner and were having their coffee and doughnuts instead of standing near her. They could have held her hand. They could have had more compassion for her. That--compassion--is something that you are not going to find over here. (Interview with Anita)

And he come in and told me I had cancer like I had the flu. He wanted to talk to me and I was still asleep, now the anesthesia, I mean I was still, I'd wake up, you know how everything is real blurry, and I seen him standing over me and he just looked at me like, he said, you know I was afraid it was cancer and it was. He said, I'll see you in my office next week. He said we'll talk about taking your breast off, and walked off from me and let me laying there. And I felt like I was dreaming. And I thought, gee what is this, that cold hearted to do that. I decided well I'm not going to let him cut my boobs off. (Focus Group 5)

Well, I go down there [county hospital] to check in, they, they get me all set up and take me to my room, and he comes strollin' in and, I mean here I go this trauma, that's traumatic, knowin' that you're going to go through something like that. He comes waltzing in and he says, 'Well we're not gonna do this today, there's no, uh'--what's the guy who checks the [another informant: 'anesthetist?'] No, ah, pathologist--'There's no pathologist here today, so just get dressed and go on back home.' Now, this is what I went through. (Focus Group 5)

Informants shared experiences of doctors' ignoring their sheer physical presence in the room.

And so help me, while we [woman and her husband] were talking to him [doctor] in his office [about the woman's cancer] his wife knocks on the door and comes in and they have a conversation, you know! (Focus Group 5)

Some of them says things that more or less dismisses you from the room. Or say something and more or less walk out. What I do is I change [doctors]. (Interview with Rita)

These behaviors were interpreted by the women to mean that the woman is nothing, an unimportant part of the service encounter. An outcome of being treated in this manner was that many of the women's interactions with health and social service providers resulted in feelings of inferiority.

And you are talked down to instead of trying to be helped.... In this part [of the country]...it's just like you are downgraded. (Interview with JoAnn)

If you don't have insurance or if you are not the right person, it's bad. And if you are low income you will be treated like low income people. (Interview with Fran)

A lot of times you go over to Social Services and they just laugh at you, 'Ho ho ho.' (Focus Group 2)

The women's descriptions of being treated like "dirt" further conveyed feelings of worthlessness and subordination.

I dread going to the hospital with them that don't have insurance. Like they treat you like you're dirt. (Focus Group 1)

They [social service workers] don't let you know, they don't, they don't let you know what help is available and that is available they make you feel like ah, like you say like dirt if you go ask for it. (Focus Group 1)

This situation was often magnified because the women already held a subordinate economic and social position in relation to the physicians.

A second common distancing behavior was providers' devaluation of the women's knowledge of their own bodies and personal experiences with their health problems.

He has a mind of his own. He is an asshole. He think's just because you are a woman, you don't know what is wrong with you. Just because he has that PH behind his name, or DR behind his name, he doesn't give you any credit for common sense.... And doctors who really sit down and talk to you and don't use their doctor's degree as 'You are dumb, I'm the doctor'--that would help a lot. (Interview with Fran)

One informant sought a physician's help for a painful discharge in her breast and was told that it was "just caffeine." She explained to him that she thought it was something more serious than caffeine because of the nature of the discharge and because she had never been a coffee drinker and consumed very low levels of caffeine. Yet the doctor insisted on the caffeine diagnosis without taking her knowledge and experiences into account.

But at any rate, he, and he, that was all he said to me...that it was just a caffeine lump, to, to watch my intake of caffeine and this and that and the other, and the discharge would go away. And that was all I got from him. I put up with that probably two or three months and ah, this place kept gettin' larger and larger. And, I thought, I'm not stupid, I know my body, this is, something is wrong with my body. (Focus Group 5)

Another woman relayed this story about one of her friends: despite repeated attempts to explain her pain and problems to county hospital workers, she was treated only for pneumonia--the hospital staff never checked her for anything else.

See they, the doctor over here, for what, four or five months?, told her that she had pneumonia, kept treating her for pneumonia. Never checked her for anything else, and finally they found out within six months time, they had to take her to another doctor, she had lupus. I mean and no treatment, you know within that length of time and already, her left lung is completely gone. I mean it's completely useless because they kept treating her for pneumonia. You know and she's telling them 'I'm hurting here, I'm doing this' [and the providers are saying] 'Well you've got pneumonia, you're just sore.' (Focus Group 2)

Thus, in addition to being treated as inferior and worthless, having their knowledge and experiences ignored and trivialized by providers was a second way that the women were minimized as persons. Informants summed up this issue as follows: "I told them you may be the doctor, but I know my own body" (Interview with Fran).

Ignoring the women's social context was a third distancing technique that minimized the person. That physicians were oblivious to the realities of what life is like for a woman

trying to manage her health care needs in this poverty-stricken community was a common theme.

I hear repeatedly from the women's stories that many providers, particularly physicians, do not understand them and their daily realities. 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, etc.; limited selection of fresh produce in grocery stores; few healthy choices in restaurants; few walking trails). (Fieldnotes 6/9/95)

In summary, providers minimized the person by ignoring the women's feelings, individuality, knowledge, and social context, as reflected in the following story.

I went to see him, and this is no exaggeration. I went in, I was on the examining table when he came in and he examined me. And if you push on this place and I'd have the discharge, it was terrible. And the pain. 'Oh, pain is good, pain is good, if you have pain that's good. And, it's just caffeine, or.' Well, I have never been a coffee drinker, you know, and just very little, it wasn't just caffeine, because I, with caffeine and that kind of thing you have, you'll build up to something. You'll have the cyst, or you'll have something. But at any rate, he, and he, that was all he said to me. And then he spent 20 minutes telling me about how he was going the next day somewhere to become a naturalized United States Citizen. And he had decided that it was the best thing he could do because he was living his American dream and he thought he may as well go ahead and have the right to vote. Now, I'm not goin' to tell, this is the truth, I was, I, all these feelings come back to me as I'm sitting here telling this. I was falling apart. And, and he expected me to be thrilled about him becoming a United States Citizen, you know. And he told me that it was just a caffeine lump, to watch my intake of caffeine and this and that and the other, and the discharge would go away. And that was all I got from him. I put up with that probably two or three months and ah, this place kept gettin' larger and larger. And, I thought, I'm not stupid, I know my body, this is, something is wrong with my body. (Focus Group 5)

## Summary

Thus it was in the service encounter that the women experienced some of the greatest barriers to health care. As discussed earlier, a common consumer expectation for good service delivery is that the provider has a consumer orientation in which he or she is attuned to consumer needs. An important value at the crux of a consumer orientation is the recognition of clients' individual worth. In particular, Fairmount County residents place a high value on recognizing individual worth and human dignity, as the discussion of egalitarianism in Chapter 3 would suggest. Yet the service encounters the women experienced ran counter to these normative expectations. The encounters were frequently dissatisfying, largely as a result of the numerous distancing behaviors of physicians. Instead of treating the women as worthwhile human beings, the doctors distanced themselves by minimizing time, contact, and the person. While any consumer would find such provider behaviors demeaning, these distancing techniques were amplified for the women in this study because of the already large status differential between themselves and the doctors. They were also perhaps more poignantly felt because the women valued egalitarian interactions.

Fiene's (1990, 1993) research in a rural Appalachian community also illustrates how an egalitarian ethic is manifest in expectations for social interactions. The women in her research believed strongly in the community norm of equality and such beliefs led to expectations regarding desirable behaviors in interpersonal interactions. Three of the norms of this "etiquette of equality" include personalization of interactions, minimization of social distance, and equal access to services. First, the women expected others to take a personal interest in them and their families. They resented when they were treated in an impersonal or stereotyped manner or when others did not understand their particular needs. Thus, personal caring and sensitivity to the needs and situations of others is one important component of the egalitarian ethic. Second, the women expected people of higher status to minimize social distances between themselves and lower status persons. In Fiene's study, some ways that this was accomplished were by downplaying signs of affluence in dress or possessions and by the widespread use of first names among all status groups. One of the most flagrant violations of this norm was "putting on airs" (i.e., acting better than others.) A third norm or expectation of social interactions was that all people should receive the same services, regardless of status level, and be treated as equals. Specifically, low-status people should not receive substandard service or be treated as inferior. Obviously, the experiences of the Fairmount County women in medical service encounters violate each and every one of these norms!

In light of the numerous barriers the women experienced in obtaining health care, both in accessing the system and within the service encounter, many of the women opted out of or minimized their use of the health care system because it did not meet their needs. The remainder of this chapter explores the numerous strategies the women adopted, within and outside the health care system, to manage their health needs in light of these difficulties.

## Managing Health

As the women's voices have illustrated, obtaining adequate health care in Fairmount County and staying healthy in this medically underserved, poverty-stricken environment was a struggle. The barriers to good health and to health care access were many, including economic and environmental conditions, maldistribution of providers and services, barriers to health care access, and service encounters that they found humiliating and dehumanizing. In spite of these barriers, the women actively engaged in numerous activities to manage their health and health care needs, which can be roughly divided into activities outside and within the formal health care system.

Many women in the community opted out of the formal health care system and managed their health and health care needs *outside* of the system. Other women *did* utilize the formal system, but they took an active role in getting the care they wanted *within* that system. It is important to explore both kinds of health management activities because understanding experiences outside of and within the formal health care system can help provide a more comprehensive account of where the health care system succeeds and fails in serving vulnerable populations. The women's health management strategies are explored in the following two sections.

### Health Management Outside the Formal Health Care System

In many instances, informants managed their health and health care needs outside the formal health care system. Health management activities included doing without any form of care, prayer, and self- and community care.

*Doing Without.* Doing without was a common theme. For instance, Rhonda had gone without a doctor's care for four years because her last experience was so negative.

The last experience was so traumatic. Gynecologist. I haven't been [to a doctor] in four years. I have not one good story about one gynecologist here. (Interview with Rhonda)

Doing without because of economic constraints was also common. Many informants discussed how lack of insurance and/or money meant they could not afford preventive and screening tests.

Oh, if they've got a Medicaid card, or some type of insurance, then some of them will do it [get preventive tests such as pap smears and mammograms]. Ah, but, somebody, for instance myself, I've not had no kind of test for six years. (Focus Group 2)

I don't go have one because I don't have no 70 and 80 dollars to pay for no pap smears. And then when you do finally go and you find out something is wrong, it's usually too late. You done waited too late. (Focus Group 1)

Similarly, informants described how their economic situation often meant doing without needed medicine.

I can't afford to go every four weeks [for my medicine] like I'm supposed to. Cause if you ain't got nothing coming in, you just can't. (Focus Group 2)

I have been known to do without medication because I do not have medical insurance.... If I do get my medicine filled for the month, it's \$230 some dollars. So some months I have to do without medication. And so I have been known to do without my blood pressure pills and my fluid pill. (Interview with Paula)

You have to have this medicine and she [my mother] has done it a time or two [not taken her medicine] without telling us. You know, sometimes like I said you, anybody had pride and, even with your family members sometimes don't want to just always seem like you're in need or let them know that you don't have. And sometimes she has been without that she needs each day you know-- not to let you know that she doesn't have her insulin, she didn't have the money to get it like that. Because the winter months puts hardship. (Focus Group 1)

Closely related to doing without care was delaying it until the last possible minute. One informant described how an infection got worse because she was unable to visit a physician early in the course of her infection. She only went to the doctor because of the severity of this particular illness--this informant typically did not see doctors at all.

...about six or seven months ago, when I had really gotten sick, it all started with a cold and I kept saying, well it'll get better, it'll get better, it'll get better. Then it wind up with infection that had hardened in my, uh chest. And actually I was really at the point of death. And then I finally called appointment over to the doctor and they told me, that I had noticed a color in my, a change in my color that's the reason why I went and I went from work, and he told me that I was at the point of death. Because I did not have insurance to go to the doctor, and I kept saying it'll get better, it'll get better, it'll get better. And then I had the asthma and then I had got the infection that harden in my chest and then I had the bronchitis. And it's all because I did not have the insurance to go to doctor. (Focus Group 1)

Decisions to seek or not seek health care were difficult and involved terrible trade offs. For instance, one informant lamented how her sister was afraid to get a mammogram because if she did have cancer, she was likely to lose her house because she could not afford the high costs of cancer treatment.

My sister found a lump in her breast...and she don't have any insurance and she's afraid to go have a mammiogram [sic] done, cause if she does have cancer, she'll lose her house.... And I told her, I said, you have to have it done.... She needs to go but she's afraid to go. And if you do go to the doctor and you do have cancer surgery they try to take her home and what she have away from her. So what does a person do? I told her, I said, you have to go, I mean you have no choice. Now, if it's cancer they'll just have to take your home, because you know, you can come live with me, but you have to go. And she's afraid I think because, she's afraid to go, she's afraid it's cancer. It really bothers me. (Focus Group 5)

The consequences of these tradeoffs were often physically painful. One woman worried, "I don't know what to do. I'll just have my migraines.... I can't afford to go [to the doctor]." The women often chose to forego care for themselves in order to afford care for their loved ones.

And that's the thing with the mothers, for instance, myself, I'll take my chirren to the doctor rather than myself cause round here most of the time the parents ... they got the children and let themself go. And it shouldn't have to be like that.... She's got to be well too, you know, to take care of the children and we ought to sympathize with her too. (Focus Group 2)

If we can just afford one ulcer medication, I make sure he [my husband] has his. And I just sit tight. I would rather for my husband; cause I'll tell you the truth. I'm going to be honest, I'll pray myself through an illness. (Interview with Paula)

This is consistent with other research showing that Appalachian women often put their own needs last (Fiene 1993).

*Prayer.* Prayer was another prevalent health management strategy. Informants often relied on their faith to help them cope with health matters.

But when I hear cancer, the only thing I do, the first thing I do is pray for 'em and that's the first thing that I think to do, that it will help them. (Focus Group 5)

And our family's a religious family you know, when something happens the first thing we do we all get together and we pray, I mean, that's the first thing. And you will find in Fairmount County that's what most people do. The people that I know.... She [my sister] said, I don't want to die, she said I have a grandbaby on the way and said I want to see the grandbaby really bad, but she said, I look at it this way, she said, if I live, she said I win and if I die I win. So it doesn't really, she said, I would like to stay around and see my grandbaby be born but she said, if it's not, you know the Lord's goin' to let that happen, she said, I won't. And she didn't. The baby was born two weeks after she died. (Focus Group 5)

And we just had to pray about it and that's it. I'm gonna be honest, I just have to, most of my sickness is just prayer. That's it. (Focus Group 1)

Prayer was the only course of action available for one informant. She knew she needed to take her child to the emergency room, but could not afford to do so and resorted to prayer to help heal her child.

I'll pray myself through an illness. Cause I've got my oil right in there beside my bed. And I'll pull that oil out right now in a minute. And I'll get my grandbaby to anoint me with oil. Cause I believe in that. I have been so deathly sick and I have woke her up during the night and tell her, you've got to anoint granny with oil. She will say, well granny what do you want me to say. I said honey, just pray an earnest prayer, if you want your grandma to feel better, ask God to help me to feel better. And I have done that. And I have done that for her. Many a night she been laying in there sick. And the other week about 2 weeks ago, I don't know what it was. She was sick, she was talking out of her head. She was throwing up. And I said, Lord, she begged me. She said granny please take me to the emergency. I know I couldn't. So I said Lord, I don't have nobody to depend on but you. And I got my oil and I anointed her with oil and it was about 4:30 that morning before she finally calmed down. (Interview with Paula)

*Self- and Community Care.* Health management strategies in the area of self- and community care included healthy behaviors and preventive care, self- and peer education, self-care, and community care. First, community women engaged in and understood 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)

So much of our health is up to us. Good health is so much our own responsibility and, you know just, to know so much and do so little is a shame. But I really believe that it's very much up to me. Diet, exercise, uh you know, just common sense things. (Focus Group 5)

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

Staying active was another way that informants stayed healthy.

Anita stays very busy with her gardening and canning (Interview Notes).

I try to work all the time.... If you don't get your exercise and keep moving, you are going to get old.... Now you take some of those people around here. They sit at home, they watch TV and they are complaining that this is wrong and that is wrong. All the time. It's where they don't get out and do anything. I get out and I put out my garden. (Interview with Helen)

Similarly, the women understood the importance of and practiced preventive measures.

I think our diet, and our self examinations [are] awfully important. Just being aware. (Focus Group 5)

I just rolled over a little bit and felt a pain, and it was very deep. And I, I always examined my breast, always, and never felt it before, and I felt, you know, I just kinda started pushing on my breast, and gee, way down deep I could feel a lump. And it was very sore so I decided well we have to check this out because it's such an odd thing, such an odd thing. (Focus Group 5)

While the women knew the importance of healthy practices, they also recognized that some of their behaviors were unhealthy and needed to be modified.

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)

Second, the women engaged in self- and peer education as another prevalent health management strategy. Informants actively sought out health-related information.

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

The only information I ever get is what I read. Cause you are not really educated here [by the doctors] I don't think, what's good and what's bad. So in order to really know what I should do for myself, I have to read. And I read a lot. I mean, when you go to the doctor, they don't explain to you what kind of diet you should have you know or ways of just keeping yourself healthy. (Interview with Elaine)

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 went well beyond self-study and actively educated 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)

And ah, what I try to do, instead of worry, well my approach I decided is to be smart, and to teach my daughter, there had been no cancer in my family, ah breast cancer. Ah, however, my daughter's now at a higher risk and so's my son--that's something we have to remember, men do get breast cancer. And so, I've tried to teach them to be smart about their bodies and to remember that they are at a higher risk than they might have thought they were. And that's how I try to treat myself too, is to be aware of my body. (Focus Group 5)

Last, when faced with illness, women relied on both themselves and each other. Self-care and community care were common health management strategies.

[When I get sick, I] do the best I can to take care of myself. I know I just lay down until I get to feeling better and then go OK. (Focus Group 3)

I don't think I have had very many experiences with health care cause I'm a person who don't go to the doctor unless I just have to. I have to be half way dead before I direct myself to the doctor. And another reason I don't go is I don't have health care [insurance]. So every time I go I have to pay out at least 35 or 45 dollars just for visiting, so I normally try to doctor myself.... It has to have been ten years or longer since I have been to the doctor. (Interview with Fran)

Numerous informants told me that they "doctored" themselves and their children and avoided visiting a doctor's office unless the illness was extremely severe (Fieldnotes 5/22/95). Informants also stressed the important role of community in coping with health matters.

Now, I tell you something I have found that's so helpful, is to be able to talk about it.... And I thank God for Susan, she helped me so much. We drove back and forth to, for our treatments some and I think we leaned on each other. We, we drew strength through each other, we, we really did. And developed such a close friendship. And ah, so I think we helped each other, I know she really helped me. (Focus Group 5)

And this place here [senior citizens' center] has been a great help to me. Yes, I don't know what kind of shape my mind woulda been in if didn't, come mix with people. You know where you have to live alone and different things, heartaches and troubles and things, you get amongst people, why it helps get your mind off what's bothering you.... It helps to talk to other people about your problems. I think it helps. (Focus Group 3)

Well if we didn't [look out for each other], nobody else would. You know country people have to look out for each other. (Interview with Helen)

As this section has illustrated, informants often managed their health and health care needs without coming into contact with the formal health care system. Such activities included doing without any form of care, prayer, healthy behaviors and preventive care, self- and peer-education, and self- and community care. While many of the women managed their health outside of the system because they did not have access to health care, others opted out of the formal health care system because it did not meet their needs. Health management activities *within* the formal health care system are discussed in the following section.

## **Health Management Within the Formal Health Care System**

Health management activities within the formal health care system included actively resisting negative stereotypes, adopting a healthy skepticism, stretching prescriptions, outshopping, and managing the system.

*Actively Resisting Negative Stereotypes.* As discussed above, the women often encountered medical service encounters that made them feel worthless. These feelings were magnified by the typically large status differential between health care providers and consumers. Strategies for dealing with such demeaning interactions were to discount providers' behaviors as unfair and for the women to affirm their own value.

They [social service workers] can be very rude about it [providing assistance]. I think there should be more people that, feeling like, everybody needs a helping hand sometime. And when somebody needs a helping hand, don't act like they are lower than you are. Because that, just because they are down on their luck at that time, that doesn't mean they are a bad person. It doesn't mean they are a free loafer. I mean you have free loafers out there. What I'm saying is a lot of times people just simply is having a hard time at that time, and I think they should be more caring and concerned. (Interview with Rita)

The women's strategies for handling assaults on their self-worth are consistent with strategies observed by Fiene (1990, 1993). In her study of women in an Appalachian community, she found that labeling offenders' behaviors was one way of dealing with being put down. When higher status people violated the women's expectations of equality, the women in her research labeled them as "snobby people" or as "people who put on airs." Fiene noted that "labels of this type have credence beyond their own social group and thus have true retaliatory power" (Fiene 1990, p. 535).

Another way of coping with the formal health care system was to adopt an attitude of skepticism toward the system.

I just beginning to wonder sometimes, if they [health care system] don't try to use you for the money. Those people that do have insurance. I had gall bladder surgery over two years ago, still with diarrhea, and continuously still going to the doctor. They never can find out what the cause is. They send you from doctor to doctor, medicine from medicine, and like I say you know, all this, no insurance pays a hundred percent, and I'm way in debt, with trying to find out the cause, or a remedy to not having diarrhea. And then they'll send you from doctor to doctor, specialist to specialist, and the cost is unreal.... I just wonder if sometimes they don't use and abuse.... I said I wonder how fast they'd find out what's wrong with you if you go in there and you don't have

insurance. Like her, you know all a sudden you get instantly cured, or they would find, you know give you the right medication, or, would they give you something so you don't come back no more. (Focus Group 1)

Well, I had one X-ray took down at Dr. \_\_\_\_\_'s office and he sent me to Berwick, the county general hospital with that X-ray and when I got over thar, they took four more X-rays right then and thar and that is too many X-rays for anybody. You're not supposed to have over two a year, if I can read what people, other people says about them. (Focus Group 3)

She [my sister] went to the emergency room and had a bill for what, about \$300? And the only thing they did was swab her son's throat and they had all this list of stuff that they had did down there. And people don't pay attention to that bill. I know when I got one it was higher, but I never thought to look at it. But they had gave her stuff on that bill that had never happened, that they had never done. So when you go to the emergency room you need to watch that stuff. I never thought that somebody was writing down they did an X-ray, or they did this, when they only swabbed your throat. And then, finally, she kept, they kept billing her and she told them that none of that stuff happened, and then it was just like she only owed a hundred some dollars. (Focus Group 1)

The more patients you've got, the more money you get. (Interview with Helen)

*Stretching Medicine.* A common health management strategy was to make medicine last longer by taking part of a pill, taking pills every other day, or stopping prescription use prematurely (Fieldnotes 5/30/95). Since many of the women could not afford the high cost of prescriptions, these activities helped them to get medicine when they otherwise could not.

So many times my husband will cheat on his high blood pressure medicine. Instead of taking two pills a day, he will take one because it is so expensive. (Interview with Rita)

Another common practice was to share medicine with others.

And then you try to, well, call somebody, 'Well have you got any antibiotics? You know, we need some antibiotics here to give this child,' you know. [Moderator: So you have to self-prescribe?] Yeah, prescribe, before you can, because who can afford to go have all this done, buy three or four different kinds of prescriptions? Then you just don't know what to do. (Focus Group 2)

A lot of times we [woman and her husband] take her [daughter's] Ibuprofen cause I can get a refill on the card [her daughter's Medicaid card]. (Interview with Rita)

The decisions regarding medicine allocation were tough ones.

Well, I'm going to be honest. OK, I'm, I was, this is truthful. My husband and myself and my daughter, we all three one day, something would of, we all three had ulcers. We all three got ulcers. Like we had one pill, and I'm going to be honest, one pill. And we just, I wanted to give it to him, and he wanted to give it to the girl, so Sally, the daughter, she finally wound up taking it. And we just had to pray about it and that's it. (Focus Group 1)

While the women recognized such practices were not ideal, the alternative was to do without medicine.

Excerpts from Focus Group Discussion on sharing medicine ("- " indicates change in speaker)

- And the thing is, and you know you're not supposed to take other people's prescriptions.
- That's the truth, but
- But, I don't know how many uh Sara done came up to me and I done took a whole bottle of her medicine.... One time I had four different kind of medicine. One with Sara's on it, one with Jimmy's on it, one with Ben's on it, and one with mine on it.
- Don't have no other choice I mean you if you, you so sick you can't hardly hold your head up.
- If somebody has the same symptoms that you have think you can make it better, take that chance, take the medicine.
- Well honey, I tell you what I had, was taking some, I know it was outdated, but it, I mean my chest.
- I have never got dated medicine.
- I had taken my baby, she was two years old and I done doubled the dose and tripled the dose.
- That's the truth. I know, when I have the, Sara have Jimmy's cough medicine and it be, it's made for kids but I go in there, just turn it up and drink it.
- Take Sara's cough syrup--if they take a tablespoon I take about four of them, cut it down. (Focus Group 1)

*Outshopping.* Outshopping is when consumers shop outside their local trade area for products and services (e.g., Gooding 1994). Many Fairmount County residents were forced to seek health care outside of the county (or do without care) because of the unavailability of specialists in areas such as obstetrics/gynecology, orthopedics, and cardiology. However, provider and service distribution was only one factor driving outshopping. Some women

sought care outside of the county because local providers treated them with disrespect and/or ignored their needs.

I went to this one doctor for one solid year and I told him, I said I've got this place on me. It's needs to be lanced, or something needs to be done. It went on for one year. So, I just got tired of it and I made an appointment at Bendersville. I had cancer. (Focus Group 2)

Another thing here, is the doctors. You can be sick, you can go in and tell them, I feel this way, and this way, this way. And they'll say, 'Well we really think you're depressed.' And you know that's what it's coming from. 'We really don't think nothing's wrong with you, you're just depressed.' You know, and you can go for five years and until you get bad off, if they happen to accidentally find it or if you can travel from here to Ellet City and pay a doctor, you know, plus your travel and everything else to see a decent doctor that might accidentally happen to find it. (Focus Group 2)

My data suggest that a primary reason that women bypassed local providers and organizations was because they perceived them to be of lower quality. For instance, one informant described some local doctors as "horse doctors...not worth diddly" (Focus Group 2).

I know I won't see Dr. \_\_\_\_\_. I wouldn't take my dog to him.... And then I have heard a lot of people say the same thing about him. He is a quack doctor. (Interview with Fran)

They say it [the local hospital] is a good hospital for anybody that's dying. They say they take real good care of a person that is on their death bed. (Interview with Helen)

The name for that, that emergency clinic over there is, 'If you check in bad you won't check out.' And that's the name they done gave it. (Focus Group 1).

The women told stories of poor quality care at the local hospital, such as misdiagnoses.

Oh, I had an experience with my daughter when she was about 6 months old, actually.... It was one night she was sick and she kept getting hotter, and hotter, and hotter. And I called the rescue squad and we took her to Casserville and Dr. \_\_\_\_\_ was the doctor on call. And he give her some medicine and said she has diarrhea and it comes from probably teething or something. I brought her back home and she kept getting crying, so my mom said well maybe you need to take her to the doctor. So I took her to the hospital...there

was a community hospital. And it was a pediatric doctor by the name of Dr. \_\_\_\_\_ who I took her to. And he immediately started working with her and said if I had waited until the morning to bring her, her temperature was so bad, she might have died. And what she had was pneumonia. And he [the other doctor] said diarrhea and give her this medicine. So I took the medicine and everything with me and he actually called the doctor and asked me if he ran a test on her or whatever. I said no they didn't do anything. And told him that he did not need to be a doctor was telling me that she was teething and had diarrhea from teething, when she could have died. (Interview with Fran)

*System Management.* Some women actively "worked" the system to meet their health care needs. For instance, working the system was one practice for obtaining prescription medicine.

Well, I tell you what I did when I needed my medicine. I went to the doctor and I told him I had, and this is when he gave me the prescription, I said, I have asthma and Jimmy has asthma and he diagnosed me and he gave me all this medicine and stuff. He gave me the same thing that he gave Jimmy and I came home and told Jimmy to go and pick that medicine up and he picked it up with his card, because he gave me two prescriptions, one for me and one for Jimmy. And that's how I got my medicine. Wasn't for that I wouldn't have been able to have got it. (Focus Group 1)

Sometimes I will say, well I wish they'd give me this and I could give it to this one. You know, or if I could get it with my medicine card, where I could pay \$15, or \$5, it would be like regardless of how much it costs. With my insurance the highest I would have to pay is \$15 if it cost \$200. But, then like I say where my sister here one of her medicines \$85 or whatever, you know then she doesn't have that money, you feel, you know, you wish it was a way, you know, not to cheat the system or to beat the system, but you wish it's a way that you could do something. You know what I'm saying, when you feel blessed that you're able to do, then you worry because others are not. And where they're needing things that are more life threatening or maybe more demanding than what, you know, you are able to live with. (Focus Group 1)

Because all of them's got arthritis and then all their doctors will prescribe it for them, but they don't have insurance. So [my husband] gives this one a bottle and that one a bottle. You know, the ones that has prescriptions for it and can't go buy it. (Interview with Helen)

Another way that community residents managed the health care system to their advantage was by obtaining Supplemental Social Security for the health benefits.

Well, I'm going to tell you something and this is, I mean it's not confidential or anything. But in my estimation so many people, now I'm not saying the ones that really deserve it, there are cases that do deserve it. But a lot of 'em try to get on SSI for the simple reason it pays for medication. It pays for medicine up to you know with a little bit, and they get so much money a month. And they are actually in better shape than someone else that's living on Social Security and you've got all your bills to pay, and you gotta pay somebody to take you somewhere, if you have to hire them. I'm lucky I can get someone to take me to the dentist. They're going theirself and they don't charge you a big fee or anything like that. (Focus Group 3)

One informant explained how she and her husband purposefully sold their business to lower their income so that their daughter could qualify for a Medicaid card.

We couldn't have, at times that she was on so much medication that we couldn't have afforded the medication. That was the purpose of my husband making sure that he had a low income. So we could get this; therefore they gave us the Medicaid card. (Interview with Rita)

### **Summary**

Accessing health care was an ongoing struggle for the women in this study. They experienced institutional barriers that differentially impacted whether and how they could access providers and services. Once in the service encounter, they faced additional obstacles through the physicians' distancing behaviors: minimizing time, contact, and the person. The service encounter often resulted in feelings of worthlessness. The women adopted numerous health management strategies, within and outside the formal health care system, to take care of themselves in light of the barriers to and within the health care system.

## **CHAPTER SIX**

### **UNEASY TENSIONS IN HEALTH CARE DELIVERY: TWO CULTURES COLLIDING**

One goal of this dissertation was to explore why vulnerable populations are slipping through the cracks of current health care systems. The voices of service providers and consumers in this rural Appalachian coal mining community revealed numerous problems in the delivery of health care to at-risk consumers.

A critical analysis of the voices of the women and the providers in Fairmount County suggests that the impersonal delivery of welfare medicine collides with the rural community for which it is meant. On one side of the medical service encounter are physicians who were educated, trained, and socialized in a medical culture that emphasizes curing disease through the application of invasive procedures and advanced technology. This dominant curing orientation is institutionalized in the design and delivery of health care in our society--a bureaucratic, cold, impersonal system that treats patients as objects. While the doctors were often motivated by compassion, the care they provided rarely broke free from the boundaries of the curing approach in which they were trained. Further, their training ill prepared them for the realities of practicing in a community with indigent consumers. On the other side of the encounter are health care consumers who celebrate family and community and value authentic, caring relationships based on norms of egalitarianism. Yet these consumers live in an impoverished community with few economic opportunities. Lacking both economic and social capital, the women rely on welfare medicine. The service encounter thus is a collision of cultures that sometimes results in a dehumanizing experience for the women.

This chapter explores these collisions, or contradictions, in health care delivery in Fairmount County. A cursory analysis might suggest that the primary collision is in the attitudes and expectations of the doctors and the consumers. This dissertation shows, rather, that the collisions exist at multiple levels: the organization of the health care system, the models of health care, the service encounter, and the outcomes of health care delivery. Table 10 is a summary of these collisions. Consistent with the critical nature of this research, the primary goal of highlighting contradictions is so they might serve as an impetus to stimulate change (e.g., Murray and Ozanne 1991; Murray, Ozanne, and Shapiro 1994). While some general directions for change are offered in this discussion, more detailed solutions are elaborated in Chapter 8.

#### **Organization of Health Care**

Contradictions exist at the structural level of the health care industry. First, equity in access is a persistent problem in the structure of the health care system. Health care in the

United States is distributed on the basis of ability to pay and the delivery and quality of such care varies widely. Our health care system is a two-tiered system: private health care predominantly serves higher income groups, and public health care serves a majority of lower income groups. The latter tier is a system of welfare medicine supported by public health insurance and is characterized by lower quality care, longer amounts of time in waiting rooms, and greater bureaucracy (Cockerham 1995). Further, the millions of consumers with no or inadequate health insurance also do not encounter equitable health care access. Thus, economic disadvantage translates into medical disadvantage. Compounding problems of inequity in our country's health care system are the maldistribution of health care providers and services and the low social capital investment facing impoverished communities like Fairmount County. The women in this study experienced all of these problems in health care inequity--they faced a public system of welfare medicine and its lower quality care (if they gained access at all), they had no or inadequate health insurance, and they lived in a medically underserved area with inadequate social capital investments in health care.

These inequities in health care delivery collided with the ethics of fairness, social equality, and social justice that are important values in Appalachian communities (e.g., Fisher 1993; Kahn 1973). This dissertation, like the work of Fiene (1990, 1993), showed that an egalitarian ethic was manifest in expectations for social interactions. That is, Fairmount County residents believed that all persons should get the same level of service regardless of status. However, their encounters with the health care system violated these expectations.

A second problem in the organization of health care is that the medical establishment's emphasis on specialized, technology-based care flew in the face of the actual needs of consumers in Fairmount County. The medical establishment produces a proliferation of specialists trained and socialized to provide highly technical, specialized care dependent on the latest medical technology. However, Fairmount County, like other rural communities, needs primary care physicians for most health care needs and the shortage of PCPs is particularly acute in rural communities (Fickenscher 1992). Further, the specialized, technology-based training ill prepared Fairmount County physicians for the realities of practicing in an impoverished, medically underserved community. First, the medicine practiced in Fairmount County could not rely on the most recent technological advances because they were often unavailable, sometimes unnecessary, and usually unaffordable. Instead, the practice of medicine in this community was driven by the skills of the doctor, such as diagnosis based on little technology and good interpersonal communication. Second, medical schools' primary focus on acute care ill prepared physicians for the practice of general medicine, most consumers' greatest need, and the broader skills this required. The doctors were forced to learn such skills on their own to get the general practice training that medical school failed to provide, yet they faced isolation from peers and continuing education. Third, specialization can lead to fragmented care with fewer and fewer doctors taking responsibility for the "whole" patient (Fuchs 1974; Light 1988). However, serving the needs of the whole patient was an important and needed part of practicing in Fairmount County because the context of

consumers' living conditions (e.g., environmental and economic risks) can adversely affect health access and status. Impoverished living conditions regularly placed them at risk for poor health.

A related collision stems from the fact that the health care system is primarily oriented toward acute care or "incident treating" as one physician informant called it. That is, the system is more focused on treating people who are sick than on keeping them healthy. Further, following treatment, impoverished consumers often return to living conditions that put them at-risk for poor health (Aday 1995; Cockerham 1995). The medical establishment overemphasizes heroic medicine at the expense of preventive care.

We keep people alive for whom there is no happy outcome, yet we do not vaccinate kids. There is a woman in Washington, D.C., who has been comatose, with no reasonable hope of recovery, since 1953. Yet in that same city the infant mortality rate is greater than in many Third World Countries (Lamm 1989, p. 59).

Further, incident treating is expensive and unaffordable for impoverished consumers.

It is clear that the current organization of health care does not adequately meet the needs of Fairmount County consumers. Solutions at this level need to address equity issues, the overemphasis on high-tech, specialized training to the neglect of general practice training, and the system's bias toward incident treating versus preventive care.

### **Models of Health Care**

A second set of contradictions emerged between the predominant curing model of health care that permeates the health care system and the women's desire for more caring health care delivery. Recall from Chapter 4 that a curing orientation focuses on disease while a caring orientation attends to consumers' social and emotional needs as well as the disease.

The curing model dominated health care delivery in Fairmount County. Consistent with a disease orientation, county physicians tended to objectify consumers as diseases, mere body parts, or problems to be fixed--not as living, breathing human beings with emotions who struggled against alarming odds. The technological favoritism of the health care system also contributed to the objectification of consumers and lack of a caring orientation. For instance, physicians served as "body mechanics" who treated the affliction but not the person (Bayles 1981). Further, the high technology, highly technical training received in medical school meant that Fairmount County doctors were not well versed in using their "eyes and ears" in the process of health care delivery. It was no wonder then that the women rarely experienced much interpersonal sensitivity in medical service encounters. Rather, the women reported feeling dirty and worthless in health care encounters. That is, the physician distancing

behaviors experienced by the women--minimizing time, contact, and the person--led to a dehumanizing service encounter. The doctors' conduct, rooted in the curing model, masked any feelings of warmth or concern so effectively that the encounter was often chilling for the women. It is distressing that the physicians, who were motivated by and displayed some elements of compassion, were virtually unaware of how the women experienced the service encounter.

The detrimental consequence of this problem or disease orientation is that health care is not addressed toward consumers as whole persons. Consumers bring much more to the medical encounter than a "disease." They bring, for example, symptoms; feelings of discomfort, unease, anxiety, or fear; and life experiences that impact and are impacted by their health status. Further, consumers' health needs and concerns are embedded in a broader social context. However, the physicians rarely investigated issues that extended beyond the immediate medical problem (e.g., environmental and cultural influences, psychosocial concerns) and how they may impact consumers' health. The fact that physicians paid little attention to the "whole patient" and rarely investigated social context issues collided with the type of broad, whole patient, context-relevant care that was desired and needed by the women in Fairmount County. For these women, like other vulnerable consumers, environmental and economic conditions are significant influences on health status (Aday 1993). Impoverished living conditions regularly place them at risk for poor health and affect their ability to access care, follow treatment plans, practice preventive care, and so on. Further, the curing model results in a narrow view of provider/consumer relationship.

Solutions at this level should explore how the strengths of both curing and caring approaches can be blended into a more effective form of health care delivery. For example, health care would benefit from incorporating both the high-tech specialized knowledge of the traditional medical model and the human-based orientation of the caring model.

### **The Service Encounter**

The medical service encounter is inherently hierarchical. This hierarchy is rooted in the curing model of health care which gives primacy to the disease and the physician who is the expert in treating the disease. Power and control are vested in the doctor; the consumer is subordinate. The manner in which consumers are treated during service encounters reinforces this dichotomy.

First, consistent with the curing model, the doctor as the expert, is in power. Yet doctors are not the only experts. The women know their own bodies and this knowledge of one's body and everyday experience is its own base of power for the women. Second, the doctors bolstered their power (and at the same time reinforced social distance) by minimizing the women and devaluing their knowledge. These practices breached community norms of egalitarianism and the desire for social distance and status differentials to be minimized.

Fairmount County consumers valued *non-hierarchical* interactions. The egalitarian ethic also means that people expect respect in social interactions. Minimizing the person impeded the medical encounter (e.g., when the women's knowledge and/or psychosocial concerns were dismissed or downplayed), and ultimately, the overall quality of care.

Third, providers viewed the women as passive and generally forced them into passive roles in the service encounter. Fairmount County physicians viewed good patients as compliant and submissive. Doctors viewed themselves, not consumers, as the primary "monitors" of health, thus ignoring the women's role in the management of their own health. Forcing the women into a passive role completely ignored their agency and ran counter to the reality that they were highly involved in managing their own health needs both within and outside of the health care system. The women were active; they monitored their health through a variety of health management activities (e.g., engaging in preventive care, actively seeking out health information and educating themselves and one another).

Problems stemming from the hierarchical nature of health care were further manifest in communication during the service encounter. The women's own words were powerful evidence of how the doctors distanced them through minimizing time and contact: hurried encounters, quick diagnoses, trial and error treatment and diagnostic techniques, diagnostic catch-alls, limited explanations and information provision, and limited touch.

On the other side of the dyad, the physician data revealed how they minimized communication. The structure of the traditional clinical interview limits both the domain of what is discussed and the participation of the consumer, and this study showed how these problems were manifest in Fairmount County health care delivery. First, physicians viewed the service encounter as only a medical exchange. The primary objective was to make a diagnosis and this objective dominated the encounter. The result was that doctors allowed only a narrow range of topics to be discussed. The women's needs outside of the immediate medical problem were largely ignored, resulting in a lack of attention to the whole person and her social context. Consumers are problems to be fixed. Second, physicians controlled the amount and nature of consumers' participation in the encounter. The women were typically allowed to participate in the encounter by describing their chief complaint and/or responding to the doctors' questions, but they had or no involvement beyond this role.

Thus the service encounter is a monologue, not a dialogue. This physician-dominated encounter results in a one-way exchange with the doctor asking the questions, controlling what information is discussed, and telling the patient what to do. Thus consumers are relegated to a passive role. Good patients are compliant and submissive.

Minimizing the women's participation in the encounter and limiting two-way exchange flew in the face of their active role in managing their health. When consumers did seek a physician's care, they wanted to be actively involved in the process. They valued shared

control and collaboration. They sought involvement in and responsibility for their health status.

In seeking solutions at this level, these tensions in the service encounter must be resolved and ways to humanize the service encounter should be explored. Doctors need to work toward humanizing their attitudes and practices. The women need to learn skills to resist the techniques that render them passive.

### **Outcomes of Health Care Delivery**

The most relevant outcome in the medical model of health care delivery is "fixing the problem" or "curing the disease." Consistent with this, Fairmount County doctors viewed curing the patient as the most important and satisfying outcome. However, in telling patients what kind of treatment to follow to fix the problem, the physicians rarely accounted for the women's social context or the realities of living in poverty. In other words, focusing on fixing the problem without accounting for limited resources does little to help consumers. For example, prescribing drugs for a consumer who has no money or insurance does not even fix the medical problem. What is needed are doctors who offer solutions that will work given limited resources. (An example of this kind of orientation is explored in Chapter 7).

Education was another outcome that the physicians viewed as extremely important. The doctors believed that poor health outcomes and health care access were largely the women's fault (e.g., they were ignorant regarding proper nutrition and healthy lifestyle habits and failed to engage in preventive care or adequately use existing services). However, education was not the problem. The women clearly understood the importance of prevention and healthy behaviors and the connection between factors such as diet and health. And this knowledge was translated into action. Contrary to the providers' focus on individual behaviors as the problem, the women linked poor health status and access to structural obstacles and problems in the service encounter.

Perhaps this traditional "depository" view of education is not the central solution to problems in health care as the doctors believed. The women *are* knowledgeable about health matters and, within their limited resources, act on this knowledge. If any form of education is needed, it is a problem posing form of education that can empower the women (Freire 1970/1986). Unfortunately, the doctors frequently blamed the women for problems in health care access and status and at the same time were blind to the women's active role in managing their health. To improve health care, solutions cannot merely focus on getting individuals to change their behavior. Both individual *and* structural changes must be addressed.

Finally, the physicians' views of relevant outcomes were narrow. The primary outcomes they stressed were curing health problems and educating the women. Yet there are many other outcomes that are relevant. The medical establishment's disease orientation means

that the focus is on consumer cure. Solutions must go beyond merely focusing on curing the disease, but on consumer well-being. A broader view of health outcomes that can help in the search for solutions is presented in the following chapter.

## **PART THREE**

### **SEEKING SOLUTIONS**

Part II, "The Service Encounter," explored health care delivery in Fairmount County through the voices of the physicians and the women and shed light on why at-risk populations are slipping through the cracks of current health care systems. Chapters 4 and 5 illuminated numerous ways that the existing health care system does not adequately meet the needs of vulnerable consumers. Chapter 6 suggested that problems in health care delivery in this community exist at a higher level than just the immediate medical service encounter--problems stem from a collision of two cultures. It also explored how these contradictions in health care delivery occur at multiple levels: the organization of the health care system, the models of health care, the service encounter, and the outcomes of health care delivery.

Consistent with the social change orientation of this research, Part III, "Seeking Solutions," explores potential solutions to improve health care delivery to at-risk populations. Chapter 7 analyzes health care delivery provided by a mobile health service in Fairmount County that was hailed by informants as an example of what is good about health care in the region. The care provided by the Healthmobile is very different from conventional health care delivery and it resolves many of the contradictions discussed in Chapter 6. Exploring good examples of health care delivery is an important part of seeking solutions to improve health care delivery for vulnerable populations. Chapter 8 includes recommendations for health care delivery to at-risk populations as well as contributions, limitations, and avenues for future research.

## CHAPTER SEVEN

### THE HEALTHMOBILE: SEEKING SOLUTIONS AND RESOLVING CONTRADICTIONS

The previous chapters illustrated that, by and large, health care delivery in Fairmount County collided with the rural community for which it was meant. Dominated by the curing or disease-centered orientation of the medical establishment and the primacy this model gives to the physician, health care delivery all too often resulted in a cold, impersonal, hierarchical, one-way, service encounter that attended to only the immediate medical problem in isolation of the person and her social context. Such encounters violated the women's self-worth, human dignity, and expectations for egalitarianism. Further, the doctors' voices showed that even though they were often motivated by compassion, the dominant curing orientation permeated their attitudes and practices.

Standing in marked contrast to this traditional medical model of health care provision was a mobile health service that provided health care in a caring manner and resolved many of the uneasy tensions that exist in the delivery of traditional medicine. Amid the voluminous negative health care experiences that the women described, the Healthmobile (HM) was praised as an example of what is good about health care.<sup>36</sup> This good example of health care offers insight into how to improve health care delivery for vulnerable populations. A primary objective of this chapter is to contribute to the search for solutions by encouraging awareness of potential alternatives to existing health care delivery.

#### Organization of Health Care

As discussed in Chapter 6, a chief problem of the organization of the health care system is inequities in access to care. These disparities include the two-tiered structure of the system, with health care and health care quality distributed based on ability to pay; the lack of or inadequate insurance coverage facing millions of consumers; and the maldistribution of providers and services, including the limited availability of general practitioners which are sorely needed in rural communities. Preceding chapters have illustrated how such inequities adversely affected Fairmount County consumers. Disparities in access often resulted in no health care access at all. And those consumers who did succeed in accessing the health care system typically faced the lower, public tier of "welfare" medicine and its corresponding

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<sup>36</sup>The HM was described in Chapter 2. Recall that the staff members are Sister Kay, the director, a certified family nurse practitioner; Andrea, a registered nurse; and Christina, a volunteer.

problems of differential treatment and difficulty finding providers to accept patients with Medicaid, no insurance, or no money to pay.

### **Reducing Inequities in Health Care Access**

The Healthmobile eliminated or reduced many disparities in health care access, both those based on ability to pay and those based on maldistribution of providers.

*Reducing Cost-Related Barriers.* First, the provision of free services meant that consumers with no or limited ability to pay could access needed services.

I do rely on Sister Kay for medicine because I don't have insurance. (Focus Group 1)

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 5/31/95)

One of today's clients needed physicals for each of her three children. She was so thankful that this service was free on the HM because the local health clinic charges \$80 per physical which was beyond her means. (Fieldnotes 5/30/95)

The region is characterized by unusually high incidences of chronic illness and abnormal high blood pressure and blood sugar levels (Conversation with Sister Kay). However, area residents could not afford regular office visits to monitor such illnesses. The Healthmobile filled this gap.

She'll [Sister Kay] try to help you in any way, whatever is a botherin' you there. Cause I go to her just to get a quick stick. And she gives me vitamins and pain pills for my sick right hand, diabetes. Cause I can't afford to go every four weeks like I'm supposed to. Cause if you ain't got nothing coming in, you just can't. (Focus Group 2)

Well, speaking about Sister Kay, as you may remember this morning, I was down on the Healthmobile this morning to have my blood pressure checked. And Sister Kay has been a blessing in that way, checking my blood pressure cause it runs kindly [sic] high. And in order for me to keep from having to go to Casserville [the county seat], the doctor wanted me to have my blood

pressure monitored at least once a week. And instead of me having to go to Casserville which is about a 30 minute drive from where I live, I can just go down about a fourth of a mile from the house, which is walking distance, and have Kay check my blood pressure and things. (Interview with Paula)

Healthmobile clients were given a small card with their personal health data (e.g., blood sugar and blood pressure readings) to help them monitor their own progress and to serve as a record for them to share with other health providers.

The HM helped increase access not only to medication and monitoring, but also to high cost services such as gynecological exams. Gynecological services were nearly impossible for many of the women to obtain, not only because of cost but also because no OB/GYNs practice in the county. Many women did without pap smears until they learned that the HM provided this service.

A lot of these people work for like \$5.00 an hour and they have families and they don't have any health insurance. And if it wasn't for the Healthmobile they would do without medical care. I have referred a lot of women to the Healthmobile as far as getting pap smears because they will go years without getting one. You know what I mean. (Interview with Rita)

I don't have no 70 and 80 dollars to pay for no pap smear. (Focus Group 1)

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)

While Healthmobile services were free, donations to help purchase gasoline and medicines were accepted.<sup>37</sup> The flow of donations was irregular and clients just made them whenever they were able.

Of course, that Healthmobile will take a donation of what we can afford. Therefore, you can afford the medical care. (Interview with Rita)

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<sup>37</sup>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.

[The Healthmobile] is within reach and everything of what we have ... there's no cost to it. You just give her a free will, if you want to give her something you could. (Focus Group 3)

Such donations were a source of both pride and ownership.

Clients are so proud when they give their donation to one of us. Donations come in many varieties--a dollar, two dollars, five dollars, occasionally ten dollars, fruit, vegetables, cookies, cake, to name a few. Today a client brought us home grown corn--he was beaming from ear to ear. The people are proud to donate and proud to share what little they have with the Healthmobile. They believe strongly in the mission of the HM and want to do their part, however small it may be, to contribute to helping serve health needs in the area. This gives them a sense of ownership in the HM. Also, I have heard several comments indicating that people in the area are proud people and don't like to get "something for nothing."<sup>38</sup> This seems to be another reason that donating is such a source of pride. (Fieldnotes 5/10/95)

This sense of ownership in the HM and pride from contributing served to reduce a second cost-related barrier to health care access. That is, the stigma of receiving free services or welfare medicine was lessened. While free and reduced fee services were available through some other sources (e.g., the local health department provided free and low cost services and clients with Medicaid sometimes incurred no out-of-pocket expenses), these alternatives often carried a stigma.

To me, I always felt the Health Department was for someone who didn't have any money at all. Nothing. No car. Or you know. I just felt funny. (Focus Group 1)

People don't like to go and ask for stuff free. They don't like to do that. That's humiliating to people. But that's what that's [health department] there for. (Focus Group 2)

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<sup>38</sup>This theme of people's aversion to getting "something for nothing" occurred repeatedly during fieldwork. For example, the Marsh Creek Community Center where I lived during field research 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 told me 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 twenty-five cents per item--this pricing strategy worked out well and continued.

Such perceptions support the idea that the public tier of the health care system is a system of welfare medicine. In fact, some consumers would not patronize the county health department or apply for Medicaid because of the attached stigma. In contrast, receiving free services on the Healthmobile did not carry this stigma, due, in part, to client pride and community ownership in the HM. (And partly because clients were not treated like public tier clients, which is discussed in a later section.)

A third way that the Healthmobile contributed to reducing inequities in access to care was by helping clients gain access to health care resources available to low income consumers. For instance, pharmaceutical companies have indigent patient assistance programs that supply free medications for qualified consumers. To participate in these programs, patients must have a health care provider certify their need for the medication and their indigent status. The HM informed clients that such programs were available and helped them prepare the applications, a service that was particularly helpful for functionally illiterate clients. Other local health care organizations rarely if ever provided this service (Fieldnotes 5/11/95). Many clients would not have medication if it were not for the free medication provided on the HM and the assistance in accessing the indigent patient programs. HM staff members also went out of their way to help find services for clients who could not 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. So she does things, pull a few strings and get us in over at [the hospital] and get one done. She finds something that you need. (Interview with JoAnn)

She [Sister Kay] tells you stuff like 'Well we've got a mammography screening at Easy Rock every couple of weeks. You need to make sure you're there.' (Interview with Kathy)

Sometimes we go to different hospitals to see if they will donate a free mammogram or maybe a free cholesterol check or something like that. Then we will pick out maybe 20 women who really needs and we will offer it to them as a gift or something like that. (Interview with Christina)

Recall from Chapter 5 that finding providers who would serve Medicaid patients or patients with no insurance or funds was a chief difficulty inherent in the process of obtaining health care. The HM staff members' active involvement in finding care for clients helped reduce this barrier.

Closely related to helping clients gain access to health care resources was helping them understand and negotiate some of the complexities of the health care system. For example,

HM staff members helped clients find the appropriate doctors, a task that was often difficult given the shortage of physicians, particularly specialists, in the area.

Appropriate referrals [are important]. Physicians ask us to take care of patients and we send people to the right doctors so they don't spend two or three visits before they get to the one they need. [R: Is that a problem?] It sometimes is because if you have limited resources and you go to the wrong doctor, that's \$50, and then you have to go to someone else, because all the specialists aren't in this county. (Interview with Sister Kay)

Say somebody has a stomach ache and they don't know who to go to you know.... I mean this is a modern health system. People go to internal medicine when they should be going to a surgeon or vice versa...they have diabetes and they're going to a surgeon. Well they're using up their money and they get frustrated so they forget it. [R: How would that happen?] This, the doctor is the nearest one. Nearest is often the one that they're going to go to first. (Interview with Sister Kay)

This assistance in entering and negotiating the system meant that clients could sometimes avoid the cost of an office call. Further, clients trusted the HM staff members more than other area health care providers to help them make decisions about when, whether, and how to use the formal health care system.

Helen said she hardly ever uses the health care system, only for emergencies. For everything else she goes to the Healthmobile. But when she does have to enter the health care system, she said she asks the HM staff to help her figure out whether to go, when to go, and who to see. For example, after her leg surgery, she was having stomach pains and turning yellow. She asked Kay whether Kay could help her or if she needed to see a doctor. Kay told her something was wrong with her liver, that she needed to see a doctor, and Kay made an appointment for her to see a specialist. Helen said thank goodness for this assistance because she couldn't afford a trip to a local doctor and that figuring out where to go on her own would have been difficult. 'There are probably hundreds of specialists. How would the average person know where to start?' She also said that she trusts the HM staff enough to tell her if she *really* needs to see a doctor. 'Other doctors might just send me to a specialist for the money, whether I really need to go or not. You know how they are.' I asked Helen if she had a primary care provider who could help her with such things. She said that Kay is her primary care provider. Helen's use of the HM to help her enter and negotiate the health care system is similar to Kathy's comment about Kay being her 'file guide' to the system. (Fieldnotes 3/14/96)

A fourth difficulty the women experienced in seeking care was receiving differential treatment and/or lower quality of care because of inability to pay or Medicaid or low income status, as discussed in Chapter 5. The Healthmobile eliminated these barriers to access. The HM accepts all consumers regardless of their ability to pay or income/insurance status, treats all clients equally, and provides quality care. These latter two points are discussed in later sections.

*Reducing Provider/Service Distribution Barriers.* By traveling to area communities, the Healthmobile decreased distance and transportation barriers to health care access that stemmed from maldistribution 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. Chavda)

For example, for Mountainbend residents (one of the Healthmobile destinations), the nearest health care facility was in the town of Berwick, which was about a 30 minute drive on narrow, windy mountain roads. Many Mountainbend residents had no transportation resources to get to Berwick.

One of today's clients described how she has a doctor in Berwick, but has no source of transportation to get that far. Angie doesn't have a car nor does she have Medicaid or any form of insurance to cover a cab. She said her neighbor has a truck but that that is not an option either because the truck is rundown and it's too risky to take it to Berwick. Angie said she knows she should have her blood pressure monitored, "but when you can't get there, you just can't." She just recently learned from a friend that the Healthmobile comes to Mountainbend, and this is her first visit. She told me "I thank the Lord for the Healthmobile so now I can keep watch on my blood pressure like I should. I think that since you'uns are so close by that I will be able to get here. I can just catch a ride with somebody else who is going."

The Healthmobile stops at Mountainbend once every other week. Another client, Jeannine, told me that if she ever needs something between Healthmobile stops, "I usually just do without it because I don't have a car either. I worry about what if there was an emergency, because I might not be able to get to Tristate [the health facility in Berwick]." (Fieldnotes 5/10/95)

Mountainbend was the most remote of the locations that the Healthmobile visited. However, many clients served at this stop lived in even more distant and isolated areas and drove up to an hour just to get to Mountainbend. Thus, they deeply felt the impact of provider and service maldistribution.

One woman shared with me today that health care access is even harder for people who live "up in the hollers." She said, "I live farther up the mountain from here [Mountainbend] at Paw Paw Holler. There's no way I can get to a doctor because the nearest one's in Berwick and that's over an hour away. It's hard getting in and out of the holler, especially to go *that far*." (Fieldnotes 5/24/95)

Another way the HM reduced distance and transportation barriers was by making home visits as needed. Home visits were made to acutely and chronically ill clients who could not travel to the HM sites. They were also made to follow up on patients after hospital discharge. While these were the "formal" reasons given for home visits, HM workers often went out of their way to attend to someone at home just because they lacked the means to get to one of the HM stops.

Kay is just like a, I just call a little traveling Gypsy, or whatever you want to call her. You know what I'm talking about. Because if it wasn't for her, speaking of this little community right here, the ones of us that don't have insurance, gosh, I don't know what we would do. You know, you have a daughter, my baby she suffered with allergies, and things. Then my neighbor and things. Then if we get a bad cold or the flu or something like that. We've got to call Sister Kay. Have you got anything Sister Kay on the health wagon. And if she has got anything, it don't take her five minutes. 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, I don't know what kind of medication she gave me but she gave me the medication and about three days I was right back on my feet again. I felt a lot better. (Interview with Paula)

The only other home health services in the county were based on ability to pay. Further, HM staff members regularly got visitors and phone calls at home.

I'm starting to wonder if the staff members ever get a break from their work! It seems like every time I'm at Kay's house she gets one or two calls from clients needing medicine or advice. Similarly, Andrea and Christina will get on the bus and say, 'So and so called this morning and wanted to know such and such,' or, 'So and so called, and I told her to come by today and we would

try to help her.' Some days clients were waiting at the bus early in the morning to get help from the staff before we left for the day. What amazes me most is that all three women just take it in stride. I think I've only seen Kay get a little aggravated about a home phone call *once* and that was someone who called repeatedly. Home phone calls are not a part of the regular service or publicized in any way. Clients just feel comfortable enough with the staff to call whenever they need. (Fieldnotes 5/15/95)

If it weren't for Sister Kay, a lot of people in this county would be in trouble. Because she helps a whole lot of people. She's always, I know she gets so tired because people call her at home and they come to her home to see her and she has to give them medicine there. And I know she gets so wore out. But she is really all that a lot of people have to rely on. Well, there's times when my little boy is sick and I can call her and tell her what's wrong with him and she will say, come on down and I'll give him some medicine and she lets me come to her house. And not too many people will do that. Hardly anybody will do that. (Interview with Elaine)

The Healthmobile also contributed to meeting Fairmount County's need for more preventive and primary care (versus incident treating) and for more general practitioners. First, a large majority of the HM's services centered around primary and preventive care. Second, as a nurse practitioner, Sister Kay met the need for more providers versed in general practice. Nurse practitioners (in comparison to doctors) "are much better versed in prevention and much better versed in ordinary everyday health care" (Dr. Waters). The HM also met the need, as articulated by the women's voices in Chapter 5, for more "care" in health care, which is discussed in the next section.

The health care delivery practices discussed in this section illustrate how the Healthmobile reduced many of the inequities inherent in the organization of our health care system. First, it resolved a chief disparity of the two-tiered structure of the system (i.e., health care access and quality are based on ability to pay). It also eliminated the related barrier of the stigma of seeking free health care services. Second, it reduced access barriers stemming from maldistribution of providers and services and the related transportation obstacles encountered in reaching what health care facilities *are* available.

### **Models of Health Care**

In contrast to the curing model that permeates health care delivery throughout the entire medical system, health care delivery on the Healthmobile was a quintessential example of the caring model. The defining aspect of the caring model--treating the whole person, including her experience of illness and her social and emotional needs--was consistently

evident in the attitudes and practices of HM workers. Specifically, HM staff members thoroughly understood and were attuned to the realities of the local environment and cared for clients within the context of their specific family situation and living conditions. But the Healthmobile staff extended the caring model even further by fostering authentic, caring relationships with clients. The care provided was perceived by clients as genuine and service provider/client relationships extended beyond the boundaries of the immediate medical relationship. The women perceived the staff members as much more than just health care providers.

### **Treating the Whole Person**

The care provided on the HM attended to the whole person, not just the immediate medical problem.

There is a mind body connection. And if we [as health providers] just deal with the body we don't very often get to the root cause of the problem.... Physicians here see maybe 60 people a day, spend about five hours in the office, and spend the rest of the time traveling or in the hospital...so all they can have time for is to address the symptoms, not the root causes of illness. Very often it is therapeutic for people to tell their story because they feel affirmed and the physical symptoms lessen, the acuity of the symptoms lessen as a result....

[Treating only the immediate medical issue] is a problem. Well they [patients] only get the immediate pharmaceutical band-aid. Because that's the most efficient, not the most effective, long-term or short-term.... The training of physicians up to now has been one track, scientific based, focused only on science as measurable data. They had to learn all the symptoms of disease and all the possible medications, and didn't get a well rounded. And the person got lost in the shuffle and the focus on treatment. The whole patient got lost in the documentation of signs and symptoms. (Interview with Sister Kay)

The staff members' understanding of and sensitivity to clients' emotions and fears was one example of how they treated the whole person.

Kay talked at length with a client today about her hyperactive child and how stressful and scary it is. It was obvious that Kay was really sensitive to the woman's feelings and that the woman got some relief from talking about it. (Fieldnotes 6/15/95)

Johnny was feeling sorry for himself today. He was down on himself for not having a job and for being dumb. He looked very depressed (I've been a little more attuned to facial expressions since the staff told me that blank emotion in

the face can be one sign of depression). He opened up some, but was still reserved and hesitant to open up completely. Kay listened actively and consoled and affirmed him, reminding him that he is smart and he is a good person. They talked about goal setting and she also suggested that he may want to talk to a friend. She told me later that she recommended a friend because Johnny does not like his therapist and because he may need to vent with someone he feels *completely* open with. (Fieldnotes 6/6/95)

These examples illustrate the humanistic nature of care on the HM. Staff members addressed human needs, not merely medical needs.

### **Attending to Social Context**

The HM staff members attended to the social context in which the women lived. While volunteering on the Healthmobile, I observed that clients' health concerns were always treated within the context of their family and specific living situation.

I was struck today on the bus by how sensitive Kay, Andrea, and Christina are to each person's individual concerns and context. 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. Hannah didn't want to go alone because of fear and because their truck was unreliable. The staff has talked with Hannah about her situation multiple times and they said that talking it out is good therapy for Hannah. Kay said 'we move Hannah inch by inch to getting her health needs met.' (Fieldnotes 5/9/96)

It was clear that the staff members understood Hannah's daily struggles and the obstacles she faced getting the surgery. They were sensitive to her situation and tried to encourage her, on her own terms, to have the procedure. Further, they supported her emotionally by talking extensively with her about her dilemmas.

The staff members were acutely aware of and sensitive to the daily struggles of living in poverty and how this impacts health. For example, Christina said that the stress of poverty is one of the biggest health problems in the area and she shared how this stress can affect people. She also understood the common tendency of women in the area to put their own needs last.<sup>39</sup>

When you have families and you've got bills and stuff to pay and there is only one person working in your family and that's just enough to pay the bills and not put food on the table. I mean that is enough to stress you out alone right there.... She is probably worrying about the, she will probably say well my family needs this or my family needs that. She puts herself last all the time. She is worrying about putting food on the table and whether her family has it before she will take care of herself. (Interview with Christina)

Similarly, Kay noted that many of the obstacles to consumers' obtaining care stem from lack of resources.

[Having difficulties with transportation] increases the cost of care. The personal costs. And the personal cost is what really determines whether people will do it [seek care] or not. [R: What do you mean by personal costs?] Family and traveling and child care, and a reliable vehicle that will go. (Interview with Kay)

It was evident that HM staff members fully understood the local environment and its impact on health care and took these factors into account when serving clients.

Lifestyle motivators are more difficult to accomplish in indigent people. Because there isn't a gym, and there isn't nutrition. (Interview with Sister Kay)

Andrea was talking with a client, Kathy, about nutrition today, suggesting to her which fruits and vegetables are least expensive. Kathy got really involved in the discussion and they both brainstormed on tasty ways to fix vegetables. On the way out, Kathy told Andrea thanks and how thankful she was to talk to

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<sup>39</sup>This was a prevalent theme in the data, as discussed in Chapter 5.

someone who understands that eating healthily is not only hard, but expensive. Kathy said it was nice not to be judged like she was by the WIC nutritionist, saying that the WIC nutritionists do not understand that getting the daily recommended servings of fruits and vegetables is beyond many Fairmount County people's reach. Kathy said her kids get the four food groups, but not the four or five servings that WIC expects because few people in the county could afford that. Andrea later told me how frustrating it is for Kathy that the WIC people don't understand and give her a hard time about it. She said it makes Kathy feel like a bad mother, when she is really working hard to provide balanced meals for her family and doing a good job given her resource constraints. (Fieldnotes 5/25/95)

Understanding local health attitudes and beliefs was also a part of providing appropriate care with attention to social context. For example, because of the stigma associated with mental health problems and services among Fairmount County residents, Sister Kay was careful to discuss mental health issues with clients in a sensitive manner and avoid words like mental illness.

When I talk with clients, I say, there are some people who can help you. You can talk with them and they will help you talk things through to help clear it up. They will give you the steps that you can take that'll get you better, feeling better. And it may be medication, it may be group work. (Interview with Sister Kay)

Local health beliefs about teeth was another issue that the staff took into account when providing care.

Christina was discussing dental care with a pregnant woman on the bus today and sharing with her where she could get low cost dental care. (I've been amazed since I started working on the bus at how many people have missing teeth and other mouth problems; the staff told me that dental problems are tremendous in the region.) The woman didn't have the resources to get there. But she also made a comment something like 'What's the point? For every baby you lose a tooth anyway.' I asked the staff members about this later in the day and they told me that this is one of the health beliefs in the area. Another belief is that most people will lose their teeth by the time they are 35. Kay explained that since the expected outcomes in the area about keeping teeth are not optimistic, then it is hard to motivate people to take care of their teeth. She also said that role models are not present to reinforce the benefits of healthy teeth. She and Christina and Andrea told me about some of the services they provide to proactively address dental issues: toothbrushing videos, demonstrations, and free samples of toothbrushes, toothpaste, and dental floss. (Fieldnotes 6/6/95)

This section and the previous one illustrate that health care delivery on the Healthmobile was the epitome of the caring model which treats the whole person and her needs, both emotional and social. Staff members attended to human needs, not just medical needs. Further, the HM staff members treated clients as individuals, not just as patients, and the provider/client relationship extended beyond the immediate boundaries of the medical relationship. The nature of this provider/client relationship is explored in the next section. The Healthmobile workers went beyond the caring model and developed authentic relationships with the women.

### **Fostering Relational Exchange**

The women perceived that the Healthmobile staff members knew them and truly cared for them as individuals, not just as clients. The staff showed *genuine* concern for them and their well-being (Interview with Kathy).

Sister Kay definitely does, she knows me, she understand me. Not anybody else. I don't think Dr. \_\_\_\_\_ has had enough time with me to really understand me at all. Just comes in and checks whatever is wrong with me and leaves. Dr. \_\_\_\_\_ too. Sister Kay is the only one that really knows me. (Interview with Elaine)

A client today contrasted the care she gets at the doctor's office versus the Healthmobile. She said that a doctor "shovels you in and out" and "don't know you." But she said HM staff members "know us and *truly* care about us. They care about you as a person." She said "I get asked about my family." (Fieldnotes 6/1/95)

I think that the women perceive her [Sister Kay] as very much interested in caring for them. (Interview with Dr. Waters)

It is obvious that the women feel valued as individuals. For example, when talking with clients, staff members are never generic. Rather, they show true interest in and care for the client and knowledge of her specific situation. Talk is always personalized, such as "How is your garden" or "How are your grandchildren" or "How did you do with that medicine?" The HM is also a very affirming place. (Fieldnotes 6/15/95)

It became increasingly evident during my fieldwork that the women perceived the staff members as *much* more than just health care providers. As opposed to a discrete relationship where parties come together briefly for an economic exchange, that is soon dissolved, the HM workers and the women had relational exchange. These women had ongoing relationships in

which they derived a complex set of emotional and personal benefits and engaged in social exchange, not just medical exchange (see Dwyer, Schurr, and Oh 1987; Macneil 1980).

The HM staff provides much more to clients than medical care. They are part of the women's support networks. This support takes many forms: listener, confidante, sounding board, resource person, cheerleader, to name a few. Sometimes the staff's greatest support role is providing comfort and hope in the midst of daily struggles and often bleak life circumstances. (Fieldnotes 6/17/95)

First, staff members were inspirational role models. The help they provided to clients extended well beyond the area of health management; it also included support for daily living. Sister Kay was referred to as an "inspiration," "mentor," and "guardian angel" (Focus Groups, Fieldnotes, and Interviews). Serving as a support person and nurturer stands in stark contrast to the physicians who viewed themselves as "saviors." The support provided by the HM staff members broke down the traditional hierarchy of medical care. Adopting a supportive role is a collaborative endeavor and reduces power differences. Adopting such a role lifts the person up while the "savior" role reinforces the subordinate status of the consumer. Second, the staff members were viewed as friends and/or family.

They're my friends. I consider them all like family. (Comment from client, Fieldnotes 5/10/95)

She [Sister Kay] is kind of like part of our family.... Well, there's times when my little boy is sick and I can call her and tell her what's wrong with him and she will say, come on down and I'll give him some medicine and she lets me come to her house. And not too many people will do that. Hardly anybody will do that. And then she will call, sometimes, if she knows he's really sick, cause he has like asthma and when he gets sick, he gets to where he can't breath very good, and she'll call and ask about him the next day and find out how he is. And he is okay. I just think she is kind of like a part of the family. (Interview with Elaine)

To me Kay is down home, talk to your big sister, your confidante, kind of like to an extent a surrogate mother you know. (Interview with Kathy)

There were many references to trust.

I put more confidence in her than anyone else I know of. (Focus Group 3)

I trust her more than I would a doctor. I really would. Because I tell you what, she'll sit down and she'll explain stuff to you and she will take time to talk to you. (Focus Group 2)

There's not a person in Fairmount County that don't know her. Everybody goes to her. Everybody trusts her. (Focus Group 2)

This trust was deeper than just trust in medical care, but embraced the type of trust characteristic of friendship. High levels of trust between partners in a relational exchange facilitate harmonization and ability to resolve conflicts (Macneil 1980).

These descriptions of HM relationships are consistent with "boundary open" transactions (e.g., Mars and Nicod 1984; Price, Arnould, and Tierney 1995; Siehl, Bowen, and Pearson 1992). Boundary open transactions are more characteristic of friendship than mere service provision and are characterized by a service encounter that is more relational than merely transactional. The customer believes that the service provider is interested in her or him as a person, and expects the provider to be actively involved and share feelings with customers. This point becomes clear when listening to the women compare their relationships between different providers. That is, most other providers are described as professional, business-like only, while Kay is described as both a provider and a friend.

I think I am more closer to her than I would be to a nurse, other nurses.... She [Sister Kay] doesn't treat us so just like professional, she just treat us like you know friends. So that makes her special. (Interview with Martha)

She loves us all. She is really good to us. I like going to her because of that. Dr. \_\_\_\_\_ just comes in, says what's the matter honey.... (Interview with Elaine)

Dr. \_\_\_\_\_ is very professional. He does listen to your complaints and he, you know, he is a good doctor. But there is not the, what word am I looking for, there's not the comfort, the personality, it's just a kind of blank effect. (Interview with Kathy)

Yet the care provided by the HM staff members transcended even descriptions of genuine concern and caring and the notion of a boundary open exchange. It was love.

When I see Sister Kay, she says Elaine, and she hugs me, always. And she takes me back and she says well what is the problem, and whatever it is, we will talk about and she will spend a lot of time talking to me if I need to. And uh she is the same with my little boy, she always hugs him and she loves my husband too. She loves us all. She is really good to us. I like going to her because of that. (Interview with Elaine)

And Sister Kay, who has done so much for the health care of this area with the Healthmobile.... Sister Kay is a mission of love. She is, she is. These people here, most of them are, even whether they act on it or not, are very religious. It's just the area, truly the Bible belt. And Sister Kay is the epitomy of compassion. Christianity. And she truly loves these people. She puts in long hours. Doesn't make a whole lot of money. I am happy to say she is affiliated with [name of hospital]. And also, there is not a large Catholic population in [our area], a lot of people might not know that. But they have made such commitment to this area. And they serve people regardless of them following their belief. They have just done so good here and Sister Kay is just a real good representative of that. You know and she is just, she is very dedicated. And the care you get with her is very mission of love. (Interview with Rhonda)

The relational exchange between HM workers and clients is consistent with some of Koemer's (1994) findings in her study of providers and their medically underserved patients in a Western community. She found that her informants' most positive medical experiences emphasized sacred (versus secular) qualities. They valued "special relationships" based on "real, deep, basic human connections" and emphasized not technical expertise or scientific knowledge, but responding to patients' human needs (Koemer 1994, p. 112-13).

In summary, the nature of care provided on the HM resolved many of the problems inherent in the curing model of health care. Staff members treated the whole person, including her experience of illness and her social and emotional needs. These encounters involved exchanges that went beyond the traditional service encounter and were relational in nature. This caring model, with its authentic concern for real people in their daily struggles, was particularly evident in the service encounter.

### **The Service Encounter**

Recall from Chapter 5 that the women encountered some of the greatest barriers to health care in the medical service encounter, largely as a result of the distancing behaviors of physicians: minimizing time, contact, and the person. Service encounters were not only dissatisfying, they were often humiliating and dehumanizing. In sharp contrast to these distancing experiences, the Healthmobile staff members' caring orientation and the informal atmosphere on the bus cultivated a comfortable, *welcoming* environment.

Kay and the girls that work with her, they make you feel welcome.... Kay makes you at ease. (Interview with Kathy)

[Some] women who come on the Healthmobile, have good insurance, have money, but they feel more comfortable with us than they do going to the doctor. (Interview with Christina)

Kay said it is important to be encouraging and not to alienate people, so that they will come again. (Fieldnotes 3/20/95)

This informal approach to care is a cornerstone of the Healthmobile's operating philosophy. Sometimes people are intimidated and/or fearful of the formality and complexity of the traditional health care system and this can serve as a barrier to health care access and quality. For example, people can get paralyzed or nervous when they encounter the system and forget what to say. The HM staff members purposively cultivate a low-anxiety, informal atmosphere to help make clients more comfortable in discussing their health concerns. This atmosphere is also conducive to learning since people are more relaxed. (Fieldnotes 3/20/95)

This section explores the nature of the service encounter on the Healthmobile. Specifically, health care delivery on the HM *maximized* time, contact (both talk and touch), and the person.

### **Maximizing Time and Contact**

Healthmobile staff members gave clients as much time as they needed and talked with them about any and all of their concerns. Service encounters on the HM were never rushed and clients never felt "pushed aside."

And she don't, she don't rush you. She'll take your blood pressure and everything and then if you have anything, you can talk to her and she don't just push you aside, I mean she'll talk to you. (Focus Group 3)

Well, Sister Kay always takes time. She is really good with me. If I have a problem, she will take me in the back and she'll sit down and she'll talk and talk with me. She tries to help me. (Interview with Elaine)

Another aspect of maximizing time and contact was conducting thorough physical exams and giving women the time and opportunity to explain their problems in their own terms (versus jumping to quick diagnoses in lieu of these practices).

I've said at least you can tell Kay if something is wrong. She'll check you out and make sure, that it is. Kay will check you out better than the doctor will. She will do a more thorough job than they will. And she probably will know what the name of it is. Really. Because, just like when I got the gallstone. She knew right off something was wrong with the liver or the gallbladder one. I don't know, the doctors just are not interested in the patients. As long as their money comes in I guess they are fine. (Interview with Helen)

Active listening and open-ended questions also helped to facilitate dialogue. These practices contributed to the client-centered (versus problem- or provider-centered) nature of health care delivery on the HM.

Kay, Andrea, and Christina are all active listeners. They give clients plenty of time to talk and never cut them off. They nod, clarify, repeat, and probe.... The encounter is the essence of a client-driven (not provider-driven) interaction. The staff members ask questions like "What would you like to talk about today" and they regularly ask "Is there anything else you want to discuss?" Such questions put clients at ease, let clients direct the interview, and leave the door open for clients to discuss any kind of issue, medical or not. Similarly, a common question I have observed for new clients is "Tell me about yourself." This question, too, promotes a client-centered encounter. (Fieldnotes 6/17/95)

Kay once saw a woman who came to the HM seeking thyroid medicine since she couldn't afford it. Kay asked "Is there anything else troubling you" and learned that this was not her primary problem. The woman "had a tumor in her breast and she had it for a year.... She had sought medical care and was told she needed \$75 to be examined" and thus did without. So by asking this question Kay was able to determine her primary problem and assist her with both problems. (Interview with Sister Kay, paraphrased)

Practices such as active listening and open-ended questions can help avoid one of the problems mentioned in Chapter 4: that is, in forming a diagnosis, physicians often use the first thing that the patient mentions in describing the chief complaint, even though the more important issues may not be mentioned until later (Beckman and Frankel 1984). Kay stressed the negative consequences that can result from not listening and asking yes/no questions.

Only recently have doctors been given listening skills. And doctors ask direct questions instead of indirect questions... Symptomatology can direct the questions doctors ask. For example, if the doctor knows all the symptoms of the disease, the client, if he's asking the client the symptoms, the client only has to say yes or no and sometimes the client will say yes inaccurately. So in the exchange, that the patient might know something more or have something else to say is overlooked. (Interview with Sister Kay)

Talk between HM workers and clients was not limited to immediate medical issues but encompassed emotional and social concerns as well.

Alice invited me for dinner at her house tonight. We discussed many things, one of which was her upcoming tests. She is going to the specialist in Ellet City for testing soon and she is afraid she may have cancer. She said one of the

things that will help her get through it is the love and concern of her friends. She said 'Those girls on the bus have been so good about talking this over with me--that I might have cancer. It's really scary but it helps to talk about it. It helps to get it out in the open. They listen to me and talk with me about it.' (close paraphrase). (Fieldnotes 5/24/95)

As Kathy said, clients can talk to HM staff members "about anything" and they "make you at ease" (Interview). Similarly, Christina said women "can talk openly" on the Healthmobile (Interview). My field research observations confirmed this.

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 make them feel comfortable enough to do so. (Fieldnotes 6/15/95)

Providing thorough explanations was another manifestation of maximizing contact. Further, the HM workers were careful to use terms the women could understand.

Despite the crowd of people needing medicine today, Kay, Andrea, and Christina thoroughly explained how and when to take the medicine to each person. Kay suggested to one client that she could write her a prescription for the same medicine at a lower cost. She explained in detail, without using any technical terms, how the new medicine comes from the same family as the one the doctor prescribed but is less expensive, and showed these comparisons to her in the book. (Fieldnotes 5/11/95)

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 5/25/95)

Well them big words scare. And I mean they scare bad...that's why Sister Kay...[is] so good. They're just down to earth. And they just, they tell you like it is.... But they don't use the big words. (Interview with Kathy)

Kay also stressed the importance of not belittling clients during communication.

[It is important] to be understood, to be able to communicate in terms that are understandable without belittling the people. Sometimes health care providers say, 'You have to use soap and water,' and that can be kind of belittling.

Instead of saying, 'It may be hard but you've got to keep this really clean.' It's more in the manner in which it is done. (Interview with Kay)

Oftentimes staff members' communication role was that of interpreter--that is, their task was to explain what physicians had done or said.

Johnny told us how he went to the hospital with migraines and the doctor told him it was anxiety. He said to Kay, 'Tell me what anxiety is--you know I'm not that smart.' (Fieldnotes 6/6/95)

They [clients] don't understand a lot of times [what the doctor tells them]. Some are, a lot of them just make believe they do understand. Some will come [to the HM] with their stuff and ask you know ... [for us] to explain what's happened to them. (Interview with Sister Kay)

Sometimes the interpretation role took the form of explaining risks and side effects of medicine. For example, one informant was not warned by her doctor that the pain medicine he prescribed could be addictive.

Well, I don't really trust him too much. [R: How come?] Because I, well I had um something wrong with my leg. My hip hurt and it hurt all the way down my leg to my, to the bone in my foot. And I went and uh he did x-rays on my back because he said he thought I had a slipped disk. Well, I didn't have a slipped disc, but he gave me a really, really strong pain medication for this and I took it and I asked Sister Kay what it was and she said it was a very addictive pain medication. And if I'd a started taking that I could have become addicted to it. And he did it another time cause I had my, something wrong with my jaws you know, the click. He gave me addictive pain medication for that too. Neither time did I even fill it. [R: So he gave you the prescription but you did not get it filled. How did you know not to get it filled.] Well cause I asked Sister Kay. (Interview with Elaine)

In a similar vein, another woman questioned whether she needed to be on so much medication and sought assistance from HM staff because the doctor "brushed her off."

A woman today said "Sometimes I feel like a walking drugstore." She brought all of her pills in a plastic bag and asked Kay to evaluate them for her. She was concerned that the doctor had put her on too much medicine. However, when she had asked him to review her medicine, 'He just brushed me off and said not to worry about it.' (Fieldnotes 5/31/95)

Another dimension of maximizing contact was the use of touch. Staff members regularly greeted clients with a hug or a handshake and also used touch during the course of conversation.

When I see Sister Kay, she says Elaine, and she hugs me, always.... And uh she is the same with my little boy, she always hugs him and she loves my husband too. [R: Do you get the hugs and all that from the doctor you see?] No. Maybe a pat. (Interview with Elaine)

Kay held Alice's hand while she was talking about how scared she was about her upcoming tests for cancer. It was a really comforting moment. (Fieldnotes 6/6/95)

Kay believed strongly in the therapeutic value of touch in health care delivery.

Sister Kay was reading an article on the bus today about therapeutic touch. I asked her about it and she shared with me that she believes very strongly in the healing effects of touch. She wants to take a class on therapeutic touch. I have observed lots of touch while working on the bus. A hug, a handshake, a pat on the back, a comforting hand on the arm or knee. I have also observed lots of open body language. It is all very warm and caring. (Fieldnotes 5/11/95)

### **Maximizing the Person**

The Healthmobile was a very affirming, humanizing place. Clients never felt "looked down on" or like less than a whole person like they did in interactions with other health and social service providers.

[The HM] is a blessing in disguise for Fairmount County to have it...people can go to and feel comfortable and be treated as people, and don't look down at us on low income people or colored. (Focus Group 1)

One woman described the difference in atmosphere between the HM and the health department. She said the HM is good, they show concern, we feel welcome. She said the health department "makes you feel like you're a number." She said she wouldn't go there anymore because of "the way they done me in the past." (Fieldnotes 5/11/95)

Quite the opposite was true--clients on the HM felt worthwhile and good about themselves. Service encounters on the HM were often empowering.

A client today told us she had not had a drink in four years and thanked the staff members for their support and encouragement. All of the staff members said they were proud of her. She was beaming. (Fieldnotes 5/23/95)

Doris was sharing with us her difficult struggle to get off nerve pills and how happy she was to have finally done it. "I can think like my old self now that I'm off that nerve medicine. I should have gotten off earlier." She thanked the staff members for their encouragement and for helping her build up the resolve to break the habit. Kay told her how proud she was of her. Christina added how she understood how hard it was for Doris because nerve pills can be habit forming. Andrea complimented her on a great accomplishment. Two other ladies on the bus chimed in with "good for you!" Another woman said she doesn't take much medicine because she knows it is not good for her and could be habit forming. Again, almost everyone on the bus said, "good for you." (Fieldnotes 6/5/95)

On the Healthmobile, social distance was minimized, which ended up maximizing the person. In other words, the HM workers treated the women as equals.

Hierarchy and power seem to be non-issues on the HM (quite a contrast to most doctor/patient relationships!). The staff members never position themselves as higher or more powerful than clients. Rather, they lift clients up by putting them and their needs and concerns at the center of the interaction. The staff members also lift clients up by valuing them. Clients' comments are valued, their knowledge and feelings are valued, they are valued as people. The collaborative nature of care provided on the HM also breaks down barriers. Further, the supportive role HM staff members play to clients fits this notion of lifting clients up.

Interactions among staff members were also nonhierarchical and collaborative. The staff worked well together, shared roles and responsibilities, and regularly consulted with one another during the course of providing care. I remember Kay telling me early during my fieldwork that she wants the work environment to be collaborative and empowering for all staff. (Fieldnotes 6/17/95)

[At the HM] it's just, just the whole atmosphere thing. Nobody, everybody is on one level, you know. (Interview with Kathy)

Kathy stressed that health care providers should "be willing to, you know, not always be the doctor and the nurse" and should instead treat patients on the same level (Interview).

Sister Kay regularly stressed the importance of having people involved in their health care. By helping the women to help themselves, Kay resolved the contradiction between health provider and client. To the extent to which the women took responsibility for their own health, they were empowered and they felt better about themselves.

The investment has got to be long term, that's the way I think about it. The more invested people are in their health care, the better the outcome will be. [R: Can you elaborate on how you get them involved?] By listening to their suggestions, making it a two-way street. (Interview with Sister Kay)

One form of client involvement was the personal health data cards given to clients for monitoring blood sugar and/or blood pressure readings. This card kept them involved in monitoring their own progress. Sister Kay also noted that sometimes procedures can be very involving. Many clients liked to watch, for example, the blood pressure monitoring procedure.

They want to see what happens, you know, each step of the way... [This way] the procedure is more involving. Participation. (Interview with Kay)

I observed that staff members helped to maintain this interest by explaining procedures as they did them.

Perhaps the greatest form of involvement was the collaborative nature of interactions on the Healthmobile.

It is important to connect with people, to be their partners. (Kay's comments, Fieldnotes 5/9/95)

Interactions on the HM are truly two-way exchanges. A dialogue, not a monologue. Information flows in both directions, from the beginning of the encounter to the end. HM staff members get the patients involved throughout the process, not just in responding to questions. (Fieldnotes 6/8/95)

These two-way, collaborative service encounters stood in marked contrast to the one-way, hierarchical interactions characteristic of the women's encounters with physicians. Another contrast between the care provided on the HM versus the traditional health care delivery system was that the HM workers did not blame the women or hold them responsible for their health problems. Rather, staff members understood the women's constraints (e.g., no money, limited resources) and worked in partnership with the women to help them get their health care needs met within these constraints.

## **Outcomes of Health Care**

One distinguishing characteristic of the Healthmobile (in contrast to the traditional medical model) was its broad view of health (i.e., health was viewed as well-being, not just the absence of disease). Yet perhaps the most dramatic way that the Healthmobile departed from traditional health care delivery was in its broad view of outcomes of health care delivery.

Anything that would improve quality of life, any skill, any resource in the community. Sharing the resources of the community. We promote that. That's a part of the broader concept [of health and health outcomes] than just being medically directed. (Interview with Sister Kay)

Further, the HM was concerned with both individual *and* community well-being and how community members could work together to meet health needs. This section explores some of the broad outcomes that the Healthmobile sought to achieve in working toward individual and community well-being.

### **Self-Care as the Most Important Outcome**

The current system wants people to be physician dependent. Our goal is to empower people to understand their own bodies and take care of themselves and maintain an optimal environment for their families. (Kay's comments, Fieldnotes 5/9/95)

A foremost concern with self-care is part of the stated mission of the Healthmobile. A key objective was to empower individuals and communities to do all they can to promote well-being and prevent illness.

Promoting and supporting self-care was a central part of health care delivery. For example, Helen did not have money or insurance for physical therapy. Kay showed her how to do her own physical therapy after a leg injury.

And then after four months he [the surgeon] let me start walking on it. It was terrible cause they said I would have to have therapy but I didn't go for therapy. I done my own. Kay showed me what to do. Kay said, Helen, she could do just as good as seeing a therapist will do. So I done it every day. And I think I can walk on it pretty good. Of course, I hobbled on it for a while, but it's all right now. It's swelled, but I guess you can expect that. (Interview with Helen)

Another example of the emphasis on self-care was the staff's suggestions for simple treatments that would fit within the clients' economic realities and daily lives.

Kay stressed that lack of resources is a constant stress in indigent communities and since each client's resources are limited, every health dollar needs to be spent as wisely as possible. Further, she stressed that knowing what kinds of remedies are affordable and available to clients is important. For example, she noted that over-the-counter Vicks Vaporub is cheap and can help give sinus relief. Oftentimes she recommends this rather than prescription medicine because medicine would be out of reach. (Fieldnotes 6/5/95)

Other simple remedies included 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 (Fieldnotes 5/10/95). Proposing such treatments showed that HM staff members truly understood that most clients could not afford expensive medication or treatment. Thus it was necessary to offer treatments that fit within the context of clients' daily lives and limited resources.

Staff members also encouraged and supported healthy behaviors as part of self-care. In contrast to the women's encounters with other health providers (particularly physicians), this encouragement did not take the form of a lecture on healthy behavior that attributed blame to and put all of the burden on the women. Rather, such discussions on the HM were collaborative and focused on strategies to incorporate such behaviors into daily living given limited resources and the realities of living in an impoverished community. Both clients and staff members regularly shared such ideas and learned from each other ways to incorporate healthier behaviors into their daily lives. Examples included where to find the lowest prices on fruits and vegetables, how to cook these items in tasty ways, and how to be creative in finding places to walk and in working physical activity into one's day (Fieldnotes 5/10/95).

### **Skill Building**

Building skills was another important outcome I observed on the Healthmobile. One element of this was empowering women to better negotiate encounters with the formal health care system.

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 5/23/95)

This building of skills extended well beyond medical issues, however, into building life skills. For example, the Healthmobile assisted families in developing and improving a wide range of 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)

The Healthmobile staff also fostered and supported leadership development.

I have seen them when they like have a leadership role. They blossom... You know where they had something they were responsible for. Outside of the home. And they got attention, and praise. (Interview with Sister Kay)

Introducing people to new things and fostering interaction with different kinds of people were other broad outcomes the HM staff supported.

Kay stressed that introducing people to new things can be very important to their well-being, particularly in an isolated community with limited resources and few activities. (Fieldnotes 5/26/95)

Kay noted that a benefit of the health fairs is the opportunity for area residents to interact with new and different people. (Interview with Sister Kay)

### **Vocalizing and Solving Problems**

The Healthmobile staff recognized that vocalizing problems was often a valuable outcome in and of itself.

Very often it is therapeutic for people to tell their story because they feel affirmed and the physical symptoms lessen, the acuity of the symptoms lessens as a result. They [provider] can address the other components [of the person's needs], the history. Like if people are in conflict, in vocalizing their conflict, say somebody has hypertension because they are in conflict, they work out the problem, they do problem-solving in vocalizing. And then there isn't overuse of medication, which reduces the cost to the patient and prevents other complications from overmedication. (Interview with Sister Kay)

This outcome is consistent with the importance of talking with others as a way of coping with and working through problems, one of the key themes in the data.

It done really helped me just to sit and talk about it. You know to think that somebody cares.... (Focus Group 1)

They found out that she [my niece] had cervical cancer. And I talked to her a lot and she was you know young, and real nervous and everything. And I think it helped a great deal to talk with her. (Focus Group 5)

Such an outcome would be unusual in traditional health care delivery since patients have a subordinate and circumscribed role. Doctors generally only allow patients to participate in the encounter by describing their chief complaint and/or responding to the doctor's questions.

Not only did staff members encourage women to vocalize their problems, but the staff also worked as partners with the women in problem-solving. Kay stressed regularly that "we can all help and learn from each other" (Fieldnotes 5/30/95). Helping the women work through their issues stood in sharp contrast to the one-way, "tell the patient what to do" mode of physicians. The collaborative problem-solving on the HM is consistent with Freire's (1970/1986) "problem-posing" education method that overcomes the teacher/student contradiction.

Through dialogue, the teacher-of-the-students and the students-of-the-teacher cease to exist and a new term emerges; teacher-student with students-teachers. The teacher is no longer merely the-one-who-teaches, but one who is himself [sic] taught in dialogue with the students, who in turn while being taught also teach. They become jointly responsible for a process in which all grow. (Freire 1970/1986, p. 67)

The Healthmobile was more than a place to talk and solve problems, it was a place to grow personally and be involved in improving community well-being. Personal growth and development and community activism were other outcomes the HM cultivated and supported.

### **The Transformational and Empowering Potential of Community**

The family-like setting of health care delivery on the HM, the caring orientation of staff members, and both the community's and clients' staunch support and "ownership" of the HM's mission and role in Fairmount County all contributed to a sense of community. One outcome of this sense of community on the bus was that it fostered learning. For example, HM clients learned from each other by sharing their stories, problems, and successes. Further, as noted earlier, HM encounters were often empowering. The sense of community

on the bus contributed to this, particularly the way the staff and the clients supported and encouraged each other in matters large and small.

The transformational and empowering potential of community has been cited by some researchers studying Appalachian communities (Eller 1987; Fisher 1993; Seitz 1995). For example, the women's organizations studied by Seitz (1995) provided opportunities in which women could grow personally and politically. Other authors have discussed the transformative potential of community "free spaces." Evans and Boyte (1986), who have developed this concept, describe free spaces as:

public places in the community...the environments in which people are able to learn a new self-respect, a deeper and more assertive group identity, public skills, and values of cooperation and civic virtue...settings between private lives and large-scale institutions where ordinary citizens can act with dignity, independence, and vision (Evans and Boyte 1986, p. 17).

Free spaces can range from families, churches, and communities to citizen organizations, self-help groups, and consumer cooperatives to strikes. In free spaces,

... 'people's history' can be connected to a systematic critique of the political economy; where participants can begin to see the connection between their concerns and those of other exploited people; where members can come to confront issues of racism and sexism; and where people can start to envision new alternatives to the world in which they live. (Fisher 1993, p. 329)

The nature of care on the Healthmobile fits these descriptions. Part of the HM's success is in empowering people of the community by providing such safe spaces to grow.

### **Summary**

The Healthmobile reduced many of the traditional inequities in health care access. It served as a quintessential example of the caring model. Care on the HM went even beyond the caring model which treats the whole person and attends to context; care on the HM fostered relational exchange. The service encounter maximized time, contact, and the person. Staff members focused on broad outcomes designed to improve individual and community well-being. The Healthmobile was a healing presence in the community.

The HM was an example of good health care delivery that relieved many of the tensions in traditional health care delivery. As such, the HM yields many ideas for alternative forms of health care. Some potential solutions are presented in the final chapter.

## CHAPTER EIGHT

### CONCLUSION

This dissertation explored why at-risk populations are failing to get their basic health care needs met. Health care delivery to one vulnerable population was examined and critiqued with the ultimate goal of envisioning service design and distribution strategies that might better serve at-risk populations. Specifically, I studied the experiences of both women and health care providers in Fairmount County, a rural Appalachian coal mining community. Consistent with the change-oriented goal of this research, a feminist approach guided this study. Women's everyday experiences in managing their health needs were explored through a detailed analysis of their health care stories told in their own words. Similarly, the world of the health care providers was examined based on interviews with them.

The voices of the women and the health care providers in Fairmount County detailed problems in health care delivery and illuminated why the current system does not meet the actual health care needs of the women or their community. These problems were organized into a set of contradictions. Uneasy tensions exist in the health care delivery system. It is a system that is designed for a world foreign to the people of the Appalachian mountains and hollers. It is a complex maze of bureaucracy, dominated by high tech wielding specialists who are best suited for serving "paying" customers. Thus, at-risk women have difficulty accessing the system. Yet once inside this system, the foreignness of this system grows. The curing model in which the physicians are versed helps to increase the chasm that exists between the world of the physicians and the world of the women. Common ground is annihilated in the service encounter, a one-way, monolithic encounter in which doctors have the power to narrow the interaction such that any needs beyond the immediate medical problem are largely ignored and the women are relegated into the role of passive consumer. The service encounter is a dehumanizing experience for the women because their emotional and social needs receive little or no attention, the reality of their daily lives is largely ignored, their knowledge is devalued, and their active role as managers of their health and well-being is undermined. But these "passive" consumers often flee this system that is designed with such little concern for their needs.

Health care delivery can be envisioned that eases and resolves many of these problems. Inexpensive solutions exist that not only serve the needs of the health care consumers but can be a force of transformation within the community. Health care delivery on the Healthmobile offered an instance of what health care could be like. The care provided on the Healthmobile exemplified the caring model of health care that focuses on the whole person. The care given on the HM can provide the impetus for envisioning health care in which women actively collaborate in their well-being and claim control over their bodies and health.

This chapter begins by discussing the substantive contributions of this research. Solutions for improving health care delivery for vulnerable populations are offered. These ideas seek to resolve the contradictions identified in this study. Many of the solutions owe inspiration to the health care delivery of the Healthmobile. These solutions are organized according to three constituencies that can benefit from these findings: the women and their community, health care delivery, and public policy. Next, theoretical and methodological contributions are reviewed. The chapter concludes with limitations and future research directions.

### **Substantive Contributions: Envisioning Alternative Forms of Health Care Delivery**

#### **Implications for the Women and Fairmount County**

Consistent with feminist research, the women of Fairmount County are the most important constituency that needs to benefit from this work. This dissertation benefited the women and their community in four ways. First, the health care solutions developed were data driven, based on the experiences of the women, with the goal of improving health care delivery to better serve their needs. Some of the recommendations came directly from the women, thus giving voice to their ideas for improving health care. Second, this research celebrated what is good about Fairmount County such as the role of community, family, and prayer. It put flesh on the idea of community, showing how residents unite to help one another in times of struggle. Third, this work celebrated the women's active role by making visible their often hidden daily activities of managing their health (Sherwin 1992; Smith 1987). Making the women's actions visible also served to highlight the extra effort that is required on their part since the health care system does not meet their needs. Fourth, this research celebrated the women's feelings and experiences by listening to and preserving their voices. The women were empowered by being able to vocalize their issues, share with others, and together discuss what alternative health care delivery systems should entail.

#### **Implications for Health Care Delivery**

In seeking solutions, we must move beyond attributing problems in health care delivery predominantly to doctors with a poor bedside manner and/or complaining or uncompliant patients. Conceptualizing tensions in health care delivery as a collision of two cultures forces us to take a broader approach to searching for solutions. It forces us to look beyond provider/consumer interactions and also consider structural problems in the medical establishment such as the inequities in the system, models of health care, and the narrow view of what health outcomes are important to consumers, their communities, and even society. Further, it forces us to look at both consumer and provider sides of the dyad as well as the organizational and social contexts in which medical interactions take place.

The solutions discussed in this section are organized into four areas: organization of health care, models of health care, the service encounter, and outcomes of health care.

*Organization of Health Care.* This study highlighted some ways that inequities in the organization of the health care system could be reduced. To reduce cost barriers, the women stressed that more free or low cost services need to be available as well as more payment options such as sliding fee scales and flexible payment plans. But reducing the expense of health care is easier said than done. Health fairs, like those co-sponsored by the Healthmobile, are one possible solution to reduce both cost and provider distribution barriers. Costs of staffing could be reduced through the increased use of volunteers. Another cost of traditional health care was the stigma of receiving welfare medicine. If consumers can become involved in community-based health care to the point where they "own" it, this stigma can be reduced as in the case of the Healthmobile. Such involvement might be encouraged by more actively including community members in fundraising and allocation of these funds. (This idea is explored in more depth in the public policy implications section).

More providers, particularly general practitioners, are needed in Fairmount County and many other medically underserved communities. But getting and keeping them was a struggle, as the data showed.<sup>40</sup> Four potential solutions for improving provider distribution and access are explored: mobile health units, mid-level practitioners, team health care, and patient advocates.

First, increasing the use of mobile health units could help reduce both cost barriers and provider distribution barriers. This form of health care delivery is relatively inexpensive in comparison to permanent facilities and has the advantage of being able to adapt to changing needs within the area. Further, by bringing care to the communities and offering free and/or reduced fee services, mobile health units can increase opportunities for consumers with limited resources to access health care.

Second, increasing mid-level practitioners (MLPs) has a great deal of potential for improving health care delivery. For example, the physicians in this study suggested that many of the problems they encountered could be handled by MLPs, which would be more cost effective and would free physicians for more difficult medical problems. Further, MLPs can help meet the need for more primary care providers in medically underserved communities. Mid-level practitioners are often more prevention oriented than doctors (recall that one of the doctors in this study stated that nurse practitioners are better versed in prevention and "ordinary everyday health care" than doctors). Further, MLPs are trained in routine care and more caring (versus curing) approaches to health care. For instance, research has shown that

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<sup>40</sup>See Scammon, Lee, and Williams (1995) for suggestions for recruiting and retaining providers in medically underserved areas.

nurse practitioners have better communication, interviewing, and counseling skills and demonstrate significantly more attention to psychosocial issues than physicians (Brody, Cole, Storey, and Wink 1976; Campbell, Mauksch, Neikirk, and Hosokawa 1990). While many physicians (including those in this study) advocate the use of mid-level practitioners only under direct supervision of a doctor, the Healthmobile documented the success of a nurse practitioner taking a more independent role in a freestanding primary care setting.

Third, health care teams that bring together providers with different expertise is another potential solution. Team care can reduce fragmentation and duplication of services. It can also provide more comprehensive, whole patient care by bringing to bear different expertise on health care problems and different orientations toward caring for consumers. The team concept has a lot of merit for improving the problem identified in this study of a lack of general medicine and preventive 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. Rather, these tasks could be better handled by other providers who have the time and interpersonal skills to achieve them.

Fourth, patient advocates, who could be resource people for multiple health and social services, might further facilitate provider distribution. Patient advocates can help consumers gain access to resources, serve as interpreters,<sup>41</sup> and negotiate the complexities of the health care system. Local women could be trained for this role. (Other ideas for community involvement in improving health care delivery are explored in the public policy implications section).

*Models of Health Care.* The high tech, specialized, disease-oriented care of the curing model is valuable in its own right. However, the Healthmobile chapter vividly illustrated the value and importance of the caring model and how this orientation in many cases is more attuned to and better serves at-risk consumers' needs. Unfortunately, the caring model gets little attention from the medical community (with the exception of the holistic emphasis in nursing education). The health care system and physicians must recognize and give more attention to the caring model. The overarching recommendation regarding models of health care is that we seek solutions at the intersection of the curing and caring models. This section explores some possibilities.

One of the problems of the curing orientation that was illustrated in this research was the lack of attention to social context. Solutions are needed that take the local environment into account (i.e., the impoverishment in Fairmount County). For example, more low tech

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<sup>41</sup>Recall from Chapter 7 that HM staff members often had to serve the role of interpreter--to explain what physicians had done or said.

solutions that can be done with limited resources are needed. Further, providers need to be more aware of difficulties faced by residents of Fairmount County and how these conditions can impact health. A deeper understanding of the local attitudes, norms, health beliefs, and values would increase the quality of care delivered. Hansen and Resick (1990) call this cultural relativism. They studied an Appalachian community and suggested that conflicts between providers (trained in the middle-class value system of the mainstream culture) and consumers in subcultures that differ from the mainstream culture can serve as obstacles to health care delivery. They suggest that providers need to adopt the attitude of cultural relativism, which "attempts to understand the situation through the context of the client's values and beliefs" (Hansen and Resick 1990, p. 1) and that cultural relativism can help reduce ethnocentric attitudes. Of course, such a solution requires a change in the education and training of physicians. While enacting such changes is difficult, grass-roots movements in areas of OB/GYN have led to changes in the health care system and offer hope and inspiration.

Changes are desperately needed in the "bed-side" manner of the physicians. Fairmount County doctors did feel compassion for their patients, but the manner in which they treated consumers was still rooted in the curing orientation that gives primacy to the disease and to the physician as the expert who treats the disease. Doctors are trained to exhibit a business-like demeanor, emotional control, and detached concern, which results in a cold service encounter and is an obstacle to communicating their concern to consumers. Solutions in this area must focus on expanding physicians' interpersonal training. Interpersonal skills need to be developed that can reveal compassion as opposed to mask it.

*The Service Encounter.* Solutions in the service encounter are proposed in the areas of internal marketing, physician training, reward and incentive structures, and service setting and atmosphere.

*Internal Marketing.* A common problem across the women's service encounters was that providers were not attuned to their needs. An area of services marketing research that might provide useful insights into redesigning medical education to focus more on consumer needs is the area of internal marketing. Two basic ideas underlie this concept. First, contact persons (i.e., those who interact directly with customers, such as physicians) are not the only employees who need to satisfy the customers. Rather, every member in the organization must focus on meeting customer needs (Gronroos 1981). Second, employees are "internal customers" who must be sold on the service and satisfied with their jobs in order to effectively serve the final consumer. A central premise of internal marketing is that satisfied employees will lead to satisfied customers, so the use of a marketing orientation and tools are used to recruit, retain, and motivate the best employees.

Using internal marketing principles to attempt to instill a value of consumer-responsive care during medical school could help improve provider-consumer interactions, and

ultimately, outcomes such as patient satisfaction and improved health. Such principles could also be useful in education and training programs for other types of health care professionals, such as nurses, allied health workers (e.g., physical, occupational, respiratory therapists), and support staff (e.g., lab technicians, receptionists, clerical workers). Since the physician is only one part of the system of providers that consumers encounter when seeking care, it is important that employees in all parts of a health care organization are trained to focus on satisfying the customer.

In the past, the health care industry thrived in spite of its failure to take a customer-oriented approach. In today's economic climate, where health care is being restructured to survive in a more competitive environment, a consumer orientation may be in the industry's own self-interest.

*Physician Training.* One of the greatest obstacles the women experienced in the service encounter was the doctors' distancing behaviors: minimizing time, contact, and the person. These behaviors are rooted in the dominant curing orientation. An overarching recommendation is that physicians receive sensitivity training in how their behaviors impact consumers. It is crucial that providers better understand how consumers experience the service encounter. Specifically, interactions which assume the consumer is passive and subordinate and/or force the consumer into such roles are not in the interest of generating good health outcomes. Interpersonal skills training would be one solution. Training to improve physician/client contact could focus on communication skills such as active listening and how to ask open-ended questions. Without the active participation of the consumer in the service encounter, diagnoses may not be accurate and treatment recommendations may be misunderstood. It would also be helpful for physicians to understand the value of touch and to realize how the lack of touch may communicate avoidance. Training to maximize the person would need to focus on respecting consumers. Consider how the service encounter of childbirth has changed to respect the experience of expectant mothers. To improve the problem of minimizing time, doctors need to quit rushing patients and avoid jumping to stereotypical conclusions just to facilitate diagnosis. The earlier recommendation about using more mid-level practitioners could also help in this regard; that is, MLPs could focus more on routine care so the doctors could have more interaction with consumers.

*Reward and Incentive Structures.* Changing physician behavior is only part of the solution to resolving problems in medical service encounters, however. Structural constraints can also adversely impact physician behavior toward consumers.<sup>42</sup> Specifically, structural disincentives in our nation's health care system can increase distance between physicians and consumers (e.g., minimizing time and communication). That is, patient loads and incentive/reward structures are not set up to facilitate good provider/consumer

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<sup>42</sup>Recall that a major premise of this dissertation is that in critiquing health care delivery and envisioning improvements to existing delivery systems, we must pay attention to both individual behavior *and* structural constraints.

interactions. Large patient loads do not allow for adequate time with patients, which can lead to rushed encounters and inadequate attention to consumers' needs and concerns. Medical schools reward research and obtaining research grants, publishing, new technology and drugs, and growth (Lewis and Sheps 1983; Ludmerer 1985). Such incentive and reward structures result in inadequate attention and priority to training medical students or cultivating physicians' interpersonal skills (AAMC 1984; Huddle 1991). Further, reimbursement systems also lead to minimizing time with patients. For example, diagnosis-related, group-based reimbursement under the Medicare system has prompted some doctors to discharge chronically ill elderly consumers before their condition stabilized (Aday 1993), thus minimizing the amount of care they received. Some of these structural disincentives should be altered to reward time spent with consumers and reward the development of improved interpersonal skills.

*Service Setting and Atmosphere.* The informal atmosphere and welcoming environment of the Healthmobile facilitated health care delivery. The no-frills nature of the bus itself (as well as its rundown nature) did not bother consumers or hinder health care delivery in any way. The physical setting is very important in service firms because customers and employees *experience* the facilities. The consumer is thus present in "the factory" (Bitner 1992, p. 70). Bitner (1992) coined the term "servicescape" to refer to a service organization's built environment (i.e., the physical surroundings versus the natural or social environment). Some might interpret the importance of physical surroundings to mean that health care settings should focus a great deal on surface appearances (e.g., the facilities and furniture should be new). But the Healthmobile setting suggests that investing money in surface appearances may be a low priority in terms of improving health care delivery because, in contrast to traditional health care settings that often can seem cold, impersonal, and even intimidating, the Healthmobile was very welcoming and comforting.

Further, since the servicescape can impact the behaviors of employees and customers as well as the nature of the interaction between them,<sup>43</sup> settings should be designed to meet both organizational and consumer needs. However, some servicescapes are designed with only organizational objectives in mind such as the layout of a physician's office designed to maximize efficiency in work flow (i.e., the reception area, waiting room, examination rooms, consultation rooms, labs, and staff offices are strategically located to facilitate the most efficient use of staff time). Alternatively, the layout might be designed with principles of *consumer* comfort and efficiency in mind. Ideally, the design of physical surroundings would consider organizational, employee, and customer needs. The success of the HM servicescape

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<sup>43</sup>Support for this idea can be found in numerous diverse disciplines such as marketing, organizational behavior, environmental psychology, human factors/ergonomics, and architecture. Bitner's (1992) work includes a nice synthesis of these literatures.

suggests that it is important to pay attention to what settings work for consumers and facilitate good interactions (e.g., reducing patient anxiety).

*Outcomes of Health Care.* The World Health Organization (WHO) defines the concept of health as "a state of complete physical, mental, and social well-being." While the health care system may advocate this broad view of health as well-being, this view is not translated into everyday medical practice. Rather, consistent with the dominant curing orientation, the most important outcome of health care delivery in Fairmount County was curing the disease or fixing the problem. Thus, a tension exists between what some health care providers say is important and what they actually do. Therefore, an overarching recommendation is that the broad view of health must be disseminated to the front line workers and be implemented at the level of the service encounter.

The Healthmobile provides some concrete examples of how a focus on broader health outcomes can be implemented in practice. By offering a wide range of assistance to clients that extends beyond just help with the immediate medical problem (e.g., helping clients access available services such as SSI, WIC, housing assistance, and food stamps), the HM helps clients cope with the daily struggles of living in poverty. What clients gain from this assistance is an important outcome of health care delivery in and of itself. That is, this support is crucial because vulnerable consumers often must deal with obtaining basic necessities (e.g., food, housing, jobs) before they can worry about how they will get to the doctor or obtain medicine. The HM staff members were cognizant of these constraints and provided care with an understanding of clients' limited resources. The provision of emotional support on the HM also helped clients to deal with the stress of living in poverty. These examples highlight that helping clients better cope with daily struggles is an important outcome of health care delivery. The HM's work with clients on personal development (e.g. leadership development) and skill-building (e.g., conflict management) are also examples of translating the broad view of health as well-being into practice.

A related recommendation is to broaden our views on consumer education. Many health care interventions and public policies are based on the assumption that a better informed consumer is the solution to health care problems. However, often education is not the most appropriate or relevant outcome on which to focus. Other outcomes must be considered. And the sole focus on education to change individual behaviors diminishes attention to the role of structure. Yet frequently practitioners and policy makers are too quick to offer education or individual behavior change as the solution without considering other alternatives. If and when consumer education is needed, we need to move beyond the conventional, monolithic, one-way, banking view of education and move toward a problem-posing form of education that can empower consumers to take care of their own needs. Such an approach would build on the active role that Fairmount County women already take in their own health management.

## **Implications for Public Policy**

This research yielded three sets of ideas for improving public policy. First, policy can benefit from the broader view of education just discussed in the previous section. Second, health care solutions and interventions should build on the strengths of local communities. Third, solutions should focus on developing and empowering active (versus passive) citizens. We need to reevaluate how we spend our health care dollars and these three suggestions offer potential alternatives. Community-based solutions and ways to involve and empower consumers are explored below.

*Building on Community Strengths.* Building on the strengths of the community, we can envision communal solutions to health care that could decrease barriers to health care access and improve health care delivery. For example, in Fairmount County people aid and assist each other and draw strength from one another during times of struggle. Other important themes in the data that illustrated the strengths of community were the women's sharing resources and information with one another, serving as self- and peer educators, and actively participating in self- and community care. Talk among the women and the role of church and prayer also served as positive contributions to individual and community well-being.

These community strengths and this "naturally occurring" collaboration suggest that community members could work together in their self-care efforts. Working together to teach one another and learn from one another resolves the tension between the health educator and the health student. For example, women could be trained to do their own blood pressure monitoring. Consumers could keep their own health journals. Women could serve as peer educators or patient advocates. The whole area of prevention could be seized by the community (e.g., videos, speakers, discussion groups). Or churches or community centers could organize groups for losing weight or regular exercise (this is currently being done in Fairmount County). Women could also organize to call and check on one another during times of convalescence. Setting up support or talk groups is another idea. One informant set up her own small group just to be able to discuss her concerns with other women (Fieldnotes 3/12/96). Recall how helpful and empowering the collaborative discussions on the HM were (e.g., talks that focused on strategies to incorporate healthy behaviors into daily living given limited resources and impoverished living conditions).

The extent to which communities could "own" their health care is really an unexplored idea. For example, community residents and organizations could contribute to a scholarship fund to help send a local resident to medical school (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.

*Involving and Empowering Consumers.* One finding of this research was that physicians viewed themselves, not consumers, as the primary monitors of health and were largely oblivious to the women's active role in managing their own health. Further, in the service encounter, the women were forced into a passive role with little or no room for involvement. In contrast, the data on the Healthmobile illustrate the importance and benefits of consumers being actively involved in their health care. The Healthmobile empowered consumers "to understand their own bodies and take care of themselves and maintain an optimal environment for their families" (Sister Kay). Further, the staff assisted consumers in developing a broad range of skills (e.g., negotiating medical service encounters, fostering leadership development). The staff members were partners with the consumers in problem-solving and working to get their health care needs met. These examples serve as models of ways to increase consumer involvement (see Roth 1994 for additional ideas). Further, by helping the women to help themselves, the HM workers resolved the tension between provider and consumer. To the extent that consumers take responsibility for their own health, they are empowered.

Recommendations to improve the service encounter should focus on both sides of the dyad. Providing consumers with skills-building training to help them better negotiate the service encounter is one possibility. Areas that need improvement are better communication and assertiveness.

### **Theoretical Contributions**

Much research in services marketing has focused on the interpersonal relationship between a service provider and customer and its importance to the overall success of the marketing effort. For example, the relationship can affect outcomes such as customer satisfaction, perceptions of service quality, and future purchase intentions (e.g., Bitner, Booms, and Tetreault 1990; Bitner, Booms, and Mohr 1994; Crosby, Evans, and Cowles 1990; Crosby and Stephens 1987; Surprenant and Solomon 1987). Yet amidst this attention to service relationships, only a narrow range of the many possible relationships that could develop between provider and client have been investigated. This range of relationships studied is narrow in three ways. First, the types of services studied are predominantly discrete (versus relational). Second, most research focuses on the contact employee (versus the consumer/provider dyad). Third, the majority of consumers studied are middle class.

This study contributes to research in services marketing by expanding the domain of provider/consumer relationships. Studying different forms of service relationships (i.e., those experienced by at-risk consumers) can expand and challenge our understanding of what makes a good/bad service encounter and what contributes to service quality. In the next sections, insights into the nature of service quality and relational exchange are offered that build on

existing work. Next, a new construct--service distance--is defined. Potential antecedents and consequences of service distance are also suggested.

### **Service Quality**

Many of the substantive recommendations of this dissertation focus on provider performance. Marketers can control provider performance in order to improve the service encounter. What skills should a provider have to contribute to a good service relationship? Existing literature on service quality suggests that a provider should offer assurances, and be more empathetic and responsive (Parasuraman, Zeithaml, and Berry 1985, 1988; Zeithaml, Berry, and Parasuraman 1988). But assurances that do not understand the social context are empty, hollow, and superficial. Further, how does a provider make something abstract like "offer more assurances" more concrete? This research suggests some concrete ways that providers can contribute to a good service relationship such as being more sensitive to the issue of touch and what lack of touch can communicate; facilitating two-way, collaborative encounters; engaging in a problem-posing style of education; and attending to the whole person and her social context.

### **Relational Exchange**

Research on relational exchange is another area in which this dissertation can help expand our conceptualizations of service relationships. Price, Arnould, and Tierney (1995) offer interesting insights into relational exchange in a service context. For example, they discuss how the extended, intimate, and affective nature of service relationships can lead to boundary open relationships. Recall from Chapter 7 that boundary open relationships are characterized by a lack of transaction-specific boundaries (i.e., a relationship more closely resembling friendship than a service transaction) and expectations that the provider is actively involved in and shares feelings with customers and is interested in them as persons. The relationships on the Healthmobile are consistent with this description.

Price, Arnould, and Tierney's work also broadens our views of the concept of relational exchange. Specifically, they develop the construct of authentic understanding.

This construct suggests that the service provider and client engage in self-revelation, expend emotional energy, and connect as individuals rather than simply performing their respective roles. It seems to capture both the perceived authenticity of the provider role, and some aspects of the boundary open (friendship) quality of relationships that developed in EAI [extended, affective, intimate] service encounters (p. 92).

As Price et al. note, some specific indicators in the service marketing literature hint at the importance of this construct, but lack development (e.g., Brown and Swartz 1989, p. 95).

The authenticity of relationships observed in their study and mine are both qualitatively different from conceptualizations and measures of empathy and courtesy in service quality research. However, even Price et al.'s conceptualization of and indicators for authentic understanding do not capture the richness of the authentic relationships observed in this study. Their measures are: "connected to my life," "revealed something personal," "invited me to reveal myself," "understood me," "seems like own person", and "out of ordinary." My research supports the importance of the ideas of genuine understanding and providing emotional support and goes a step further by illustrating how such support is practiced (e.g., how the HM staff members support clients in numerous ways such as aiding their struggles to meet basic needs, and helping them through skill building and cultivating a free space for vocalizing and solving problems).

My research also suggests some other avenues that are worthy of consideration in further developing the authentic understanding construct. For example, the nature of the caring orientation of health care delivery with its focus on the whole person and social context may help contribute to the development of this construct. Further, the Healthmobile data in my research suggest that other important aspects of an authentic relationship may be reducing social distance; maximizing time, contact, and the person; enhancing consumer involvement and empowerment; and fostering collaborative, two-way encounters.

### **Service Distance**

Through expanding the domain of service encounters studied, this research also identified an important dimension of service relationships that is worthy of further exploration. A primary tension in the data was the distance between providers and consumers, which I will refer to as "service distance." Distance is a dimension of service relationships that is unexplored in the literature with the exception of a study by Goodwin and Frame (1989). Their study focused on age and status differences and forms of address as indicators of social distance. The current research shows that notions of service distance must be broadened. The remainder of this section describes service distance by discussing how it is manifest in the Fairmount County service encounters, and then suggests antecedents to and outcomes of service distance. Understanding service distance can enrich our understanding of the service encounter and service relationships.

Service distance was manifest in Fairmount County service encounters through the minimization of time and communication. Physicians minimized time through such practices as rushing the encounter, formulating quick diagnoses in lieu of thorough examinations or thorough medical interviews, using trial and error diagnostic and treatment techniques, and relying on diagnostic catch-alls such as "nerves" and depression. Communication in the service encounter was largely a one-way exchange in which information flowed predominantly from doctor to patient. Manifestations of doctors' minimizing communication were allowing only a narrow range of topics, limiting explanations and information provision, minimizing

consumer participation in the encounter, and avoiding touch. Thus, service distance was an important construct for understanding the medical encounter.

Service distance arose in part because of a collision of two cultures in which traditional health care delivery collided with the rural community for which it was intended. This collision is multi-layered and different levels of the collision were articulated in Chapter 6. Thus, an important antecedent of service distance was a mismatch of provider and consumer orientations. This mismatch in many ways reflects the agentic and communal patterns of social and linguistic interaction described in the sociolinguistic literature.<sup>44</sup>

Agency manifests itself in self-protection, self-assertion, and self-expansion; communion manifests itself in the sense of being at one with other organisms. Agency manifests itself in the formation of separations; communion in the lack of separations. Agency manifests itself in isolation, alienation and aloneness; communion in contact, openness, and union. Agency manifests itself in the urge to master; communion in noncontractual cooperation. Agency manifests itself in the repression of feeling and impulse; communion in the lack and removal of repression (Bakan 1966, p. 15).

Table 11 provides a summary of characteristics of agentic and communal orientations.

The physicians' orientation, driven by the curing model and imparted in medical school, was agentic. Their worldview and medical practices were based on hierarchy, power, and personal control. They had an instrumental perspective, the tendency to view others as objects to be used/manipulated as one sees fit (Spence 1983). That is, women were just diseases to be fixed and the primary objective of the service encounter was to make a diagnosis. Recall that the danger of this instrumental, curing perspective is that the physicians largely ignored the women's needs that extended beyond the immediate medical problem as well as their social context. Thus interpersonal contact was minimized and social distance was maximized. In contrast, the Appalachian women's orientation was communal. They valued being a part of the community. They also valued egalitarianism and collaborative interactions.

While the mismatch of provider-consumer orientations was an important antecedent of service distance, critical health care outcomes were also a result of service distance. For physicians, curing the disease is the most important outcome. In the services marketing and health care marketing literatures, service quality and customer satisfaction are the two

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<sup>44</sup>See Bakan (1966), Carlson (1971), Goodwin (1990), Maltz and Borker (1982), and Tannen (1990). For related consumer research, see, e.g., Hirschman (1991) and Larsen (1993).

outcomes that have received most attention.<sup>45</sup> While curing the disease, service quality, and service satisfaction are indeed important outcomes, this study suggested additional outcomes that have received little or no attention in the services marketing literature. First, the data illustrated the importance of feeling ownership over one's health and the process of seeking care. This notion of ownership is an area of untapped potential in services marketing. Perhaps it could be studied within the realm of consumer satisfaction research. Second, services marketing identifies service exit and outshopping as important outcomes. Yet the activities of the women in this study went well beyond exiting the service--many of the women opted out of the service encounter entirely. This finding suggests that we need to study service *nonuse* in addition to service exit and outshopping.

Third, this study suggests that other important outcomes are being able to talk with and trust providers, being involved and collaborating in the encounter, and reducing stress, as well as the outcomes of consumer empowerment and well-being. The importance of involvement, collaboration, and empowerment to a successful service encounter were particularly evident on the Healthmobile. Perhaps future research would benefit from more investigation of how these outcomes can impact the service encounter and service quality perceptions. Other researchers have also supported the call for attention to other outcomes besides the traditional ones studied. Roth (1994), for example, suggests that consumers' values or desired end states such as involvement, control, empowerment, trust, peace of mind, and quality of life are also important outcomes. Pendleton (1983) emphasizes the importance of considering a variety of health outcomes in evaluating medical encounters. He distinguishes between immediate outcomes (e.g., satisfaction with an encounter, memory for the physician's instructions and explanations, changes in a patient's concern about his/her problem), intermediate outcomes (e.g., patient compliance with instructions), and long-term outcomes (e.g., changes in health status, long-term changes in health understanding).<sup>46</sup> Improved dialogue with health providers and reduction of uncertainty and stress are other examples of immediate and intermediate outcomes that have been identified as important to consumers (Peyrot, Cooper, and Schnapf 1993; Roth 1994). The relative importance of outcomes among consumers is likely to vary based on factors such as the health need being addressed, individual characteristics (e.g., age, race, and income), and the setting in which health care occurs. This area is worthy of further exploration.

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<sup>45</sup>Service quality is essential to the success of health care organizations. For example, high service quality can improve service firms' market share, profits, and cost savings (Zeithaml, Berry, and Parasuraman 1988). Further, service quality can positively affect patients' satisfaction, future patronage intentions, and compliance with treatment recommendations (McAlexander, Kaldenberg, and Koenig 1994; O'Connor, Shewchuk, and Carney 1994; Swartz and Bowen 1989).

<sup>46</sup>Pendleton (1983) defines health understanding as a patient's attitudes and beliefs about health, illness, and medical treatment.

## **Methodological Contributions**

This dissertation used a feminist approach and methods for exploring sensitive topics such as health care. Feminist methods are relatively new to marketing and consumer research, so this research contributes by demonstrating their usefulness. Feminist techniques, such as minimizing power differences between the researcher and informants (i.e., stressing my role as a student and learner), allow for the generation of richer data than may be possible with traditional methods. But, as this dissertation demonstrated, perhaps the most important methodological contribution is showing the power of a feminist approach for generating a wide range of practical solutions that consider the needs of at-risk consumers.

## **Limitations**

It is easy to be humbled by the number and scope of limitations in any single study. Perhaps I am most concerned with how my perspective might have limited my findings. In particular, I am certain I was more moved and attuned to the voices of the women, perhaps even to the detriment of my ability to listen to the health care providers. While I was conscious of these sympathies and sought to challenge my emergent themes, I may not always have been even handed. Perhaps this imbalance is most evident in my failure to do any engaged observation in a formal health care setting such as a hospital emergency room or a health care clinic. (Unfortunately, all research must come to an end at some point!) More problems could have been illuminated and solutions generated by exploring both non-traditional and traditional forms of health care delivery.

Similarly, my study encompassed one group of consumers in one Appalachian community. While many of my findings probably would be relevant to Appalachia in general, other counties have their own unique problems and would need their own unique solutions. In no way do I want my findings to perpetuate the myth of a homogenous Appalachian community or consumer.

## **Future Research Directions**

Given the aforementioned limitations, future research might explore tensions in health care delivery in a more formal delivery setting. In addition, future research might investigate whether other vulnerable populations could benefit from the insights gained in this dissertation. Do some of these results extend beyond Fairmount County to other Appalachian communities? Would these solutions be relevant to other types of impoverished and/or rural communities? For example, do at-risk African American women in cities face the same misfit with traditional forms of welfare medicine?

Future research might also seek out other good examples of health care delivery to see if some of the same themes and patterns hold up. New or expanded solutions of what makes good health care delivery might be identified. It would be interesting to find out if these other good examples work because they also resolve the tensions in traditional care identified here.

Finally, another direction is to further investigate the power of community to facilitate improvement of life in vulnerable populations. Communal impulses, such as those found in this study (e.g., sharing resources, peer education), are probably evident in other disadvantaged populations and in domains beyond health care. The transformative power of community is an area of untapped potential.

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## **Appendix A**

### **Overview of Fairmount County Women's Health Project**

A team of Virginia Tech researchers interested in women's health issues, in partnership with the Fairmount County Women's Health Collective,<sup>1</sup> 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" (FCWH Project Grant Proposal, 1993). 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 by women in other rural areas (Grant Proposal).

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" (Grant Proposal).

Project team members have presented quick summaries of this data in order to share preliminary results with Fairmount County residents and community leaders, and conference presentations about some facets of this project have been given by some of the research team members, but this rich data source has not yet been rigorously analyzed.<sup>2</sup>

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<sup>1</sup>The Fairmount County Women's Health Collective is an informal group of community women concerned about health care issues of women in the county. The group formed in 1992 out of concern that preventive health care services, specifically pap smears and mammograms, were not being well utilized by area women. The group is currently comprised of nurses, social workers, physicians, and a health educator.

<sup>2</sup>A notable exception is a master's thesis by one of the team members. This thesis is not cited to maintain confidentiality of the community.

## **Appendix B**

### **Summary of Healthmobile Services**

**Preventive and Primary Services** - Screening procedures include blood pressure readings, blood glucose monitoring, hemoglobin readings, pap smears, breast exams, urinalysis, immunizations, and assessment of circulatory problems. Other services include provision of medication, emergency care, and physical exams. Services to pregnant women include pregnancy testing, prenatal care, and follow-up care with newborns.

**Provider and Resource Referrals** - The Healthmobile is a partner to other area health and social service providers and organizations. The HM assists clients by making provider referrals and physicians often refer clients to the Healthmobile for monitoring and follow-up teaching. The HM thus extends physician services by providing these services. The HM also provides information to clients to help them access available resources such as SSI, WIC, housing assistance, and food stamps.

**Counseling Services** - Counseling is provided in areas such as diabetes management, family planning, sexuality, crisis management, weight management, tobacco use, exercise, and nutrition. The Healthmobile supports families through education and counseling in areas such as aggression and conflict management, budgeting, and maintaining a healthy family unit.

**Health Fairs** - The Healthmobile collaborates with other community organizations to sponsor health fairs approximately every two months at various locations such as community centers, low income housing projects, factories, and community events. Mammograms, cholesterol screening, health risk appraisals, and preventive education are just a few of the services offered. An additional function of the health fairs is to sensitize visiting practitioners to the needs of rural people and the need for more family practitioners.

## **Appendix C**

### **Informed Consent for Research Participants**

**Title of Project: A Critical Analysis of Health Care Delivery in Fairmount County**

#### **PURPOSE/BENEFITS OF RESEARCH**

My name is Renée Gravois Lee and I am a Ph.D. student in consumer research at Virginia Tech. This is an invitation to you to participate in my dissertation research. It is a study of health care delivery in Fairmount County. I am interested in learning about the health needs and concerns of Fairmount County women and their experiences with the health care system.

Your opinions and experiences are important to this research. Your participation in this project will help contribute to a better understanding of the health care delivery system in Fairmount County and where it succeeds and fails in meeting the needs of its residents. The ultimate goal of this research is to suggest how health care organizations in the area could be changed to better serve county residents.

While I can offer you no financial compensation, the results of the study will be available to all participants. Please let me know if you would like a summary of the results and/or a copy of the final written study.

#### **PROCEDURES/CONFIDENTIALITY AND ANONYMITY**

If you decide to participate in this research, I will ask you to give me up to three hours of your time for interviewing, spread out over one to two interviews. I understand that some of the information you may choose to share with me may be sensitive. Anything you say during the interview will remain confidential.

At no time will your name be associated with your responses. Only my doctoral advisor, Dr. Julie Ozanne, and me will have access to the data that would identify you. In any articles or reports based on this data, the identities of all participants and places will be concealed in such a way that quoted comments cannot be attributed to particular individuals. You may, if you desire, review all data (for example, transcripts, tapes, fieldnotes) before they are written up and make corrections, deletions, or additions.

If you have any questions regarding any aspect of this study, please contact me or my doctoral advisor.

Renée Gravois Lee, Doctoral Student, (703) 552-4340 (home)  
or (703) 231-6949 (office)  
Julie L. Ozanne, Associate Professor, (703) 231-7006 (office)

both at: Department of Marketing, Pamplin Hall 2016  
Virginia Polytechnic Institute and State University  
Blacksburg, VA 24061-0236

## **FREEDOM TO WITHDRAW**

Participation in this research is completely voluntary and you are free to withdraw from this study at any time without penalty. You may refuse to answer any question(s) you so choose.

## **APPROVAL OF RESEARCH**

This research project has been approved, as required, by Virginia Tech's Institutional Review Board for projects involving human subjects. Should you have any questions or concerns about this research or its conduct, you may contact:

Renée Gravois Lee, Principal Investigator, 231-6949  
Julie L. Ozanne, Faculty Advisor, 231-7006  
Ernest R. Stout, Institutional Review Board Chairman, 231-9359

## **PARTICIPANT'S PERMISSION**

I have read and understand the informed consent and conditions of this project. I give my voluntary consent for participation in this research. I have received a copy of this form to keep.

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name

I, the undersigned, have defined and fully explained the investigation to the above participant.

\_\_\_\_\_  
Investigator's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name

**Table 1**  
**Focus Group Participants**  
**Fairmount County Women's Health Project**

<u>Group</u>	<u>Number of Participants</u>
Low Income Housing Complex	6
Senior Citizens' Center	8
African American Women's Group	11
Oakwood Community Group <sup>3</sup>	7
Cancer Survivors Group I	6
Cancer Survivors Group II	6
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Total Participants	44

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<sup>3</sup>This group was comprised of women recruited from the town of Oakwood. One reason for selecting Oakwood was to sample across four different towns in Fairmount County. Further, since Oakwood is somewhat isolated due to its location on the far southwest end of the County, it has its own unique subculture. Another factor contributing to the subculture of Oakwood is the closeknit, action- oriented nature of the community. In fact, it is so closeknit that project team members could only gain access by having a local contact do the recruiting for this focus group.

Oakwood is known for being proactive and for the way its residents band together as a united front to address issues facing the community. For example, when the town was auctioned, residents banded together to find ways to buy their homes to prevent the homes from being sold to outside investors who might evict them or raise the rent. When the local post office threatened to close, community residents banded together to prevent this from happening. Similarly, Oakwood residents had to fight together to obtain needed sewer and water lines. Many of the women in this focus group, therefore, are representative of Appalachian community activists working for change.

**Table 2**  
**Profiles of Women Interviewed<sup>4</sup>**

Pseudonyms of Women: Fran, JoAnn, Helen, Rita, Paula, Anita, Elaine, Rhonda, Kathy, Martha, Mary Ann

Demographics

Age: 3 early to mid 30s, 3 mid 40s, 4 early 50s, 1 early 60s

Race: 3 African American, 8 white

Marital Status: 2 single, 1 separated (long-term), 8 married

Insurance: 3 none, 1 Medicaid, 3 parents have no insurance but children have Medicaid,  
1 husband has insurance (retired miner), 2 have insurance through husbands' retirement  
(miner, military)

Health Care Usage/Problems

Nature of health problems (overlapping categories)

5 chronic (heart disease, high blood pressure, diabetes)

3 acute instances for selves or family

1 child with disability

2 children with asthma

5 everyday health issues

Extent of contact with the formal health care system

4 none (only go to Healthmobile; have gone to hospital for emergencies for selves or family)

3 none for self/seek care for children

2 moderate

2 high

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<sup>4</sup>Summary (versus individual) descriptions are provided to ensure confidentiality of informants.

## Interview Information

### Settings:

6 informants' homes

5 other: 1 local restaurant, 2 offices, 1 activity room at church, 1 community center<sup>5</sup>

### Method of Contact:

3 met on Healthmobile

3 met through frequent contact (they are "regulars" on HM and volunteers at community center)

1 met through community activities (i.e., Readers' Theater presentations)

1 referral from Sister Kay

1 referral from an interview informant

1 woman referred herself

1 I contacted mother of informant (I had met her at her daughters' house on previous occasions)

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<sup>5</sup>The community center was like a "second home" for this informant.

**Table 3**  
**Participants in Semi-Structured Interviews**  
**Fairmount County Women's Health Project**

Health Providers (7 interviews)

Private Practice

- Family physician
- Internist

County Hospital

- Director of nursing services
- Director of cardiopulmonary services

County Health District

- Director of services (M.D.)

Healthmobile

- Nurse practitioner
- Volunteer assistant

Community Leaders (8 interviews)

School Board

- Director of federal programs
- High school principal
- Assistant high school principal
- Elementary school principal

Community Center

- Community organizer

Local Newspaper

- Managing editor

Local Church

- Minister
- Historian/business owner

Social Service Providers (7 interviews)

Department of Social Services

- Director
- Social worker for seniors

School Board

- School social worker (and former nurse)

Board of Aging

- Seniors' representative

County Administration

- Chief administrator

Sheriff's Office

- Deputy sheriff/sergeant
- Investigator

Pseudonyms of providers that are quoted in this study: Nurse Martin, Sister Kay, Christina, Mr. Vega, Ms. Rinker, Dr. Waters, Dr. Bahrani, Dr. Robertson.

**Table 4**  
**Profiles of Providers Interviewed<sup>6</sup>**

Pseudonyms of Providers: Sister Kay, Dr. Alloju, Dr. Chavda, Dr. Sandoral, Dr. Thomson, Dr. Waters

Professional Role/Setting

2 solo family practice physicians (1 of which is chief of staff at a local hospital)  
2 doctors at a federally funded clinic serving indigent clients on a sliding fee scale  
(1 is an internal medicine specialist, 1 is a generalist (but trained in general surgery))  
1 emergency room physician  
1 certified family nurse practitioner

Training

3 in family practice  
1 in internal medicine  
1 in general surgery  
1 in emergency medicine

Place of Origin/Race

2 from Phillipines  
1 from Syria  
1 from Boston (white)  
1 from Fairmount County (white)  
1 from an Appalachian coal mining community in another state (white)

Gender

4 males  
2 females

Years practicing in county

5 for 15+ years  
1 for 2 years<sup>7</sup>

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<sup>6</sup>Summary (versus individual) descriptions are provided to ensure confidentiality of informants.

<sup>7</sup>Practicing in Fairmount County was this physician's first assignment following his residency. Working in a medically underserved community is a condition of paying back his medical school loans to the government.

**Table 5**  
**Summary of Evolving Design and**  
**Data Collection Activities**

**Field Entry and Broad Exploration of Community Health Issues**

Fairmount County Women's Health Project Data  
6 Focus Group Interviews with community women  
21 Semi-Structured Interviews  
- Health care providers  
- Social service providers  
- Community leaders

Secondary data  
Area health organizations/services  
Census

Appalachian activities

**Deep Immersion**

Engaged Observation and Informal Interviews  
Healthmobile  
Daily community life

In-Depth Interviews  
Women (11)  
Physicians (5)  
Healthmobile Director

**Table 6**  
**Focus Group Interview Questions and Probes**  
**Fairmount County Women's Health Project**

<u>Question</u>	<u>Relevant Domain Explored in Current Study</u>
What are your health problems? What do you worry about? (yourself? your family? your community?)	Health Related Needs and Concerns
What do you do when someone in your family gets sick? (When you get sick? When someone in your community gets sick?)	Service Utilization/ Nonutilization; How Health Needs are Managed
Optional Question: What do you think are the reasons why people get sick in Fairmount County?	Environmental/Cultural Factors Affecting Health Status
Are there any things that get in the way of getting health care? Please describe them.	Barriers to Health Care Access/Utilization
What do you think about the following local services in Fairmount County: doctors, nurses, hospitals, public health clinics?	Perceptions of Availability and Quality of Services
If you could get anything to make you and your family more healthy, what would you do?	Services Needed; Proposed Solutions to Health Problems in County
Are there any problems relating to women's health that we haven't talked about?	Health Related Needs and Concerns

**Table 7**  
**Semi-Structured Interview Questions**  
**Fairmount County Women's Health Project**

I am here representing the Fairmount County Women's Health Collective. We want to know what you think about women's health issues and health care services here in Fairmount County.

Informants' Job/Profession/Activities

- 1) For the record, please state your name and tell me about your professional role here in the community. What is your professional title and what activities does that include?
- 2) What are the community's expectations of you?
- 3) What are the different "hats" you wear in this community? What are the various things you do outside of your professional role?

Health Problems for Women in Fairmount County

- 4) Speaking generally, what do you think are the most important health problems faced by women in Fairmount County?
- 5) Let's talk about each of these. We would like to know how important these issues are to you and what you would do to address these issues given unlimited resources.

For each problem identified, ask

- a) On a scale of 1 to 10, how important is this issue to you? to the community?
  - b) Let's say you had unlimited resources . . . money, people, time, whatever . . . How would you go about working on this issue?
- 6) What are the differences in health status between women in Fairmount County and more urban areas? Give me an example of what urban areas you are thinking of.
  - 7) What do you think are the reasons why women get sick in Fairmount County?
  - 8) Let's discuss each of those reasons. For each one, please tell me what you think is the best way to lessen or get rid of that problem. Let's start with . . .

## Health Services

- 9) When women first get sick in Fairmount County, what do they do? Why do you think they do that?
- 10) Where do they go? Why?
- 11) Is this different for men or children? Why?
- 12) On this sheet is a list of local services.<sup>8</sup> I would like you to go through the list and tell me what services you think are accepted and used by women here and why you think they are or are not accepted.
- 13) What would you say are the main barriers to women getting health care in this county? For each one, on a scale of 1 to 10, how important do you think this barrier is for women in the community? Again, given unlimited resources, what would you suggest to get rid of this barrier?
- 14) What health-related services do you think are lacking in Fairmount County?
- 15) You have identified (list services) as needed services. Using the list on this sheet,<sup>9</sup> who do you think should provide these services, and how?
- 16) What would you say is the most pressing need for women here?
- 17) Given unlimited resources, what would you do to meet that need?

## Health Organizations

- 18) How do referrals work between different health care providers in Fairmount County?
- 19) In some communities, there is a history of people and groups having trouble working together. Do you know if anything like that happens here in Fairmount County? Why do you think that happens?
- 20) What are the groups that you work with? Why do you like to work with them?

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<sup>8</sup>Items on list: doctors, nurses, hospitals, public health clinics, others.

<sup>9</sup>Items on list: government, private companies, nonprofit organizations, public-private partnerships, hospitals, clinics, doctors, mid-level practitioners, nurses.

- 21) Are there any groups that you prefer not to work with? Why?
- 22) Is there any formal way that groups can meet or develop cooperative ventures? For example, do you get together with other groups like your own and talk about doing a project together? Do you think that meeting like that would be helpful?
- 23) How well would you say that the local government works with State and Federal-level agencies? In particular, I am asking about health services, but I am interested in social services overall as well.

#### Broad Women's Health Issues

- 24) This question is a little difficult. I'd like to know what you think are some of the common ideas about health problems in the county. Think of the people you deal with every day. What do THEY say are the problems? What do THEY worry about?
- 25) Do you think that other people like you think the same thing? Do they share your opinions? Who are those other people you are thinking of?
- 26) Thinking about women and health overall in Fairmount County . . . What would you do to make women healthy? Where would you start?
- 27) Before we finish, is there anything else you want to talk about? When this interview was set up, what were you expecting to discuss? Is there anything that we have not talked about?

On behalf of the Fairmount County Women's Health Collective, thank you for your time and help.

**Table 8**  
**Domains for Exploration in In-Depth Interviews with Women**

**Domain 1: Usage** - Type and frequency of contact with health care system

Please tell me about how you and your family use the health care system. I am interested in what for and how often.

**Domain 2: Good and Bad Health Care Stories**

I'd like to know about some of your best and worst health care experiences.

Probes: What made it good or bad?  
How did that make you feel?  
How did you react?

**Domain 2a: Quality of care**

Please tell me about the quality of health care you have received.

Probes: When have you gotten good (bad) quality care?  
What was different about the health care quality between the good and bad experiences?

**Domain 3: Health Care Providers**

Please tell me about your relationships with the providers you have seen.

Probes: Please compare and contrast different providers.  
Please compare and contrast different relationships with providers.  
Probe on good and bad relationships.  
Please describe how you were treated in the good (bad) situation.

**Domain 4: Obstacles and Opportunities**

Please tell me about some of the difficulties you face getting health care.  
Please tell me about some of the things that facilitate your getting health care.  
Please tell me about the ways you take care of your self that may not involve going to the doctor.

**Domain 5: Solutions**

How could things be changed for you to be healthier?  
How could the health care system be improved? locally? nationally?

**Table 9**  
**Domains for Exploration in In-Depth Interviews with Providers**

**Domain 1: Best and Worst Medical Encounters**

(Define the medical encounter as interaction between doctor and patient and everything involved during that encounter.)

Please describe some of your best and worst medical encounters.

**Domain 2: Constraints and Opportunities**

a) Please tell me about some of the constraints you face as a doctor.

Probes: What is a typical day like for you?

Probe on constraints if not brought up (e.g., workload, facility)

b) How about some of the opportunities that facilitate your work?

**Domain 3: Service Encounter**

Please describe some recent medical encounters. Think of a patient that was typical (atypical) and describe the encounter and what makes it typical (atypical).

Probes: Tell me about how the encounter proceeds. How long? Who talks? About what?

**Domain 4: Solutions**

What recommendations would you make to improve health care delivery in Fairmount County?

**Table 10**  
**Contradictions**

**Medical Establishment**

**Appalachian Community**

Organization of Health Care

Inequities in Access

- 2-Tiered system
- Many consumers with no or inadequate insurance
- Maldistribution of providers and services
- Low social capital investment

Ethic of Fairness and Social Justice

- Expectations of equal access and treatment regardless of status

Emphasis of the health care system

- Specialists versed in high tech care
  
- Acute care/incident treatment

Actual health care needs of community

- Generalists with broad range of skills (e.g., human-based, adapting to limited resources)
- Preventive focus needed; incident treatment unaffordable

Models of Health Care

Curing Orientation

- Disease and Problem Oriented
  
- Social Context is ignored or marginalized
- Narrow view of consumer/provider relationship

Caring Orientation

- Whole Person and Community Oriented
- Social context gives life meaning
- Broad view of consumer/provider relationship

The Service Encounter

Hierarchical

- Physician is expert; has power and control

Value nonhierarchical/egalitarian

- Women are experts, too--know bodies; value shared control

- Reinforce social distance; minimize person
- Consumers often viewed as passive

- Expect others to minimize social distance; expect egalitarianism
- Women are active; manage their health within and outside system

Limited Communication

- Limited range of topics
- Low consumer participation
- Limit 2-way exchange

Value communication

- Broad range of topics
- Value active consumer involvement
- Value 2-way, collaborative exchange

Outcomes of Health Care

Narrow, curative view (treat immediate problem)

Broad view of outcomes needed that focus on whole person and well-being (e.g., involvement, empowerment, skill building)

Dehumanization

Expect respect, to be treated as person

Health is an individual responsibility; solutions directed at individual behavior; one-way view of education (banking concept)

Health is more than individual responsibility; solutions implicate structure and individual; two-way education needed (problem-posing)

**Table 11**  
**Characteristics of Agentic and Communal Orientations**

<u>Agentic</u>	<u>Communal</u>
Impersonal view of world	Community view of world
Self as autonomous from world	Self defined in social context
Favor hierarchical patterns of interaction	Favor non-hierarchical patterns of interaction
Instrumental goals and orientation	Shared, cooperative, mutual goals and orientation
Reinforce social distance	Minimize social distance

FIGURE ONE

**VITA**  
**RENEE GRAVOIS LEE**

Renée Gravois Lee, daughter of Ticker Gravois and the late J. J. Gravois, was born (1/23/66) and raised in Baton Rouge, Louisiana. She is married to David M. Lee of Metairie, Louisiana.

She holds a B.A. in Marketing and Management from Southeastern Louisiana University in Hammond, Louisiana, and a M.B.A. with a concentration in Management from the University of Houston. Prior to beginning doctoral study at Virginia Tech, Renée was employed as a services analyst by Shell Oil Company. She worked at Shell's head office in Houston, Texas in the areas of corporate travel and corporate real estate. Then she transferred to Shell Western Exploration and Production Inc., also in Houston, and worked in environmental compliance. She was with Shell for approximately five years.

Renée's substantive research interests are in the areas of social marketing and public policy, advertising, and services marketing. Some of her specific interests include the delivery of health care to vulnerable populations and the social consequences of advertising. Her theoretical interests include the contributions of critical, feminist, and sociological theories to marketing and consumer research. Recent publications and conference presentations include:

Bristol, Julia M., Renée Gravois Lee, and Michelle R. Hunt (1995), "Race and Ideology: African American Images in Television Advertising," *Journal of Public Policy and Marketing*, 14 (Spring), Ronald Paul Hill, ed., 48-59.

Lee, Renée G. and Jeff B. Murray (1995), "A Framework for Critiquing the Dysfunctions of Advertising: The Base-Superstructure Metaphor," *Advances in Consumer Research*, 22, Mita Sujan and Frank Kardes, eds., Provo, UT: Association for Consumer Research, 139-143.

Lee, Renée Gravois and Julie L. Ozanne (1996), "Two Cultures Colliding: A Critical Analysis of Health Care Delivery in a Rural Appalachian Coal Community," presented at the *Marketing and Public Policy Conference*, Washington, DC, May 18.

Virginia Tech Rural Women's Health Research Team (1995), "Empowering Appalachian Women: Using Performance Techniques to Effect Change in Health Care," presented at the *Appalachian Studies Conference*, Morgantown, WV, March 18.

\_\_\_\_\_ (1994) "The Politics of Culture: Coalition Building and Women's Health," presented at the *Appalachian Studies Conference*, Blacksburg, VA, March 12.

In August, 1996, Renée will begin her academic career as an assistant professor of marketing at Quinnipiac College in Hamden, Connecticut.