Catalytic Innovations in Appalachia Ohio Health Care:

The Storying of Health Care in a Mobile Clinic

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Karen Sickels Deardorff

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This dissertation titled
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The Storying of Health Care in a Mobile Clinic

by
KAREN SICKELS DEARDORFF

has been approved for
the School of Communication Studies
and the Scripps College of Communication by

__________________________________________

Lynn M. Harter
Associate Professor of Communication Studies

__________________________________________

Gregory J. Shepherd
Dean, Scripps College of Communication
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Director of Dissertation: Lynn M. Harter

In this study I explored the storying of health in the midst of Appalachian women living in poverty. The patients who use the free medical services offered by the Ohio University College of Medicine’s Community Health Programs (CHP) have tainted and damaged identities from the stigma and stereotypes associated with living in poverty. They are marginalized and rendered virtually (in)visible—the skeletons in the poverty closet of the United States.

The CHP advances an alternative script of health care by breaking down the barriers (lack of money/resources, fear, stigma, pride, flexibility, mobility, and health legacies) which prevent or impede their patients from accessing the free and reduced health care they so desperately need. Through this alternative script of care, CHP staff members challenge the status quo of traditional biomedical care and they work to narrow the chasm of visible (in)visibility their patients straddle daily.

By drawing on feminist and narrative sensibilities, I provide a rich ethnographic account of how a counter-narrative of medicine—an alternative web of relations among characters who are living out plots that differ from hegemonic ones—can disrupt the dominant scripts so often taken for granted as natural and fixed, in this case scripts that accompany the biomedical model. Collectively, these insights contribute new knowledge to the body of work in health communication by exploring the standpoints of those who...
have been rendered invisible through the hegemonic discourses and practices associated with traditional biomedical care.

Three methodologies were used to collect discourse related to the Community Health Program, poverty, and the storied nature of health and healing. These methodologies were: Informal and in-depth interviews, participant observations, and document analysis. The results are encompassed in three themes which include discussions of how narrative activity works to foster healing and empowerment, how the storied nature of health care is shaped by the mobile nature of the health clinics, and what role counter-narratives play in challenging the traditional biomedical and dominant scripts. Practical implications for the CHP, limitations, and directions for future research are also discussed.

Approved: _____________________________________________________________

Lynn M. Harter

Associate Professor of Communication Studies
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Ours is a voluntary walk of life. A person can fall into being a store manager or broker, but not a professor. We must choose it, aim at it, and persist in it for many years. This highlights the importance of our personal motivations, matters that are systematically omitted from our research reports and CV’s. Some of us come to this profession for no more reason than that it is intellectually engaging. But many choose this path (or hold to it) because it offers the chance of helping people, individually or in groups. (Hample, 2008, p. 319).

I stumbled onto the pathway of becoming a professor either quite by accident or perhaps through a stroke of sheer luck. For you see, I didn’t know anything about becoming a professor. Sure I had heard of them, but I never actually met one until I was almost 20 years old.

My first stroke of good luck was in becoming employed as a secretary in the Department of Linguistics at Ohio University in 1983. My second stroke of good luck was having Mark Orbe as my very first work study student that year. I have to begin this acknowledgement page by thanking Mark for encouraging me to begin my studies at Ohio University and for turning me on to communication studies as a nontraditional, first generation, undergraduate college student. Over the past 26 years, Mark has become a good friend, a brother, and a cheerleader (and I’ve had the pleasure of being Aunt Karen to his three beautiful children). Sometimes people are placed in our pathways for a reason—I am glad Mark happened to be placed in mine.

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And, as I journey along the pathway of professorship, my hope is that I never forget the obligation I have to use my position, my knowledge, and my words to help people, individually or in groups.
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CHAPTER ONE: PROBLEM STATEMENT

“Poverty, the extent of relative deprivation, and the processes of social exclusion in a society have a major impact on the health of its population” (Shaw, Dorling, & Smith, 1999, p. 196).

The stories of our lives often sit dormant until a current comes along and stirs the stones of our memories in the river bed. Although the interaction happened 45 years ago when I was only five years old, I remember the day like it was yesterday. I remember the examination room and table, the smells, the older physician with a bushy mustache and graying hair. I remember the pain and fear of being held down as the nurse gave me a series of shots and I remember screaming and crying as I had no idea what was being done to me or why it was being done. Had I been really bad and was I being punished for something? Why was my mom letting these mean people hurt me? I heard the doctor tell my mom that I was high strung, and I wondered if that meant I was going to die. Certain that something even worse was going to happen to me, I became hysterical and earned a hard swat from my mom. The truth was that I had no idea why I was getting shots or why the shots were necessary. No one thought it important to include me in what was happening or to try to lessen my fears. The first thing I didn’t know about this experience was that I was receiving childhood immunizations so that I could begin first grade. The second thing I didn’t know was that I was a poor child of Appalachia and that my mom took me to a free clinic because we didn’t have money to pay for the immunizations. And, the third thing I didn’t know was that 45 years later this experience of growing up in
poverty with virtually no financial means of obtaining medical care would lead me to the research that I would conduct for my dissertation.

Little did I know when Dr. Lynn Harter asked me to join her research team four years ago to work with the Ohio University College of Osteopathic Medicine’s Community Service Program (now called the Community Health Program and referenced herein as CHP) that I would become immersed in a topic that would so deeply resonate with my lived experiences. Dr. Harter knew of my experience with and interest in poverty as experienced by Appalachian women, knew of my interest in the discourse and empowerment facilitated by narratives, and knew of my growing interest in health care related issues.

The mission of the CHP’s mobile health and free medical clinics is to provide health care to communities with traditionally underserved populations—particularly Appalachian women—who either cannot afford mainstream medical care or who have difficulties accessing medical care for themselves and their children. Through the services provided by the CHP, women are empowered to share, and rewrite, their stories of health and illness, and they are empowered as well to take action for themselves and their children by seeking and receiving the health care they might otherwise not be able to obtain.

My study responds to Buzzanell’s (1994) call for communication scholars to “investigate the subordinated, to focus on the interactions in ordinary lives and to explore the standpoints of those who have been rendered invisible by their absence in theory and research” (p. 340) and Frey’s (1998) call to approach social justice from a communication perspective as a means of engagement with, and an advocacy for, the
economically, socially, and politically under sourced. Lupton (1995) explained the responsibility that we as scholars hold:

Health communication has the role of identifying hegemonic discourses, promoting the notion that resistance is possible, and assisting individuals and groups in the processes and skills of lobbying and media advocacy aimed at reframing and resisting oppressive discourses through the sophisticated use of language. (p. 64).

Embracing these calls and responsibilities, I drew on feminist and narrative sensibilities to provide an ethnographic account of the Ohio University College of Osteopathic Medicine’s Community Health Program (CHP) and its endeavor to address the poverty and health-related issues of one particularly disadvantaged group—women and children living in poverty. In particular I worked with those who reside in the southeastern portion of Appalachia Ohio—sites of bleak poverty and limited access to quality and affordable health care. The free or reduced health care provided by the CHP includes: breast and cervical cancer screenings to uninsured women, free medical clinic services to the uninsured who live at or below 200% of the poverty level, healthy adult screenings (glucose, blood pressure, and cholesterol) for at-risk individuals, and an adult and child immunization program which is available to all patients regardless of socio-economic status. Last year the CHP provided more than $1 million in various health services to its patients (Ludwig & Phillips, 2009).

To conduct this study, I immersed myself in the worlds of the mobile health clinic—its rhythms, rituals, and routines. By engaging in participant observation, the collection of trace artifacts and documents, and in-depth interviews, I moved between
stories performed and stories told by participants to offer a portrait of health care in settings too often unacknowledged by health communication scholars. Health communication scholarship has been critiqued for its implicit assumptions about the contexts of health care (i.e., primary care physicians’ offices, hospitals). Sharf (1993), for example, argued, “It is insufficient and perhaps misleading to examine clinical communication as if all doctors, patients, and settings are essentially comparable. Taking account of contextual variability will sharpen the utility of our work and clarify which findings transcend these distinctions” (p. 37). Over a decade later, similar calls continue to be heard as Harter and colleagues (2008) argued, “Communication scholars have remained notably silent about the organizing of health care in non-traditional settings” (p. 314).

My hope with this research is to extend the communication discipline’s theoretical and practical reach to include alternative forms of organizing health care resources. Narrative theory’s attention to the importance of context provides a robust lens through which to expand our discipline’s traditional understandings of health care settings. The mobile health clinic offers a unique opportunity to empirically enrich literature by exploring the storied nature of health and health care amidst ever-shifting scenes of activity.

In order to set the stage for my study, the first section of Chapter 1 will provide important background information about how health care is impacted and experienced by women and children living in poverty. Although I would have embraced the richness that adult male patients would have brought to the study, the majority of the patients I encountered during my observation in the mobile clinics were women and children living
in poverty. In the next section, I describe how the socioeconomic conditions faced by those living in Appalachia influence their health care decisions. In the third section, I discuss how mobile health clinics have provided an alternative way of organizing health care resources for traditionally underserved populations. In chapter two, I articulate my theoretical sensibilities as they apply to this project and then use those sensibilities to read current theory and research that pertains to this dissertation.

The Impact of Poverty on Health Care

In a report prepared for the Task Force on Poverty at the Center for American Progress, Holzer, Schanzenbach, Duncan, and Ludwig (2007) focused on the economic and social costs of poverty among children growing up in poverty and their quality of health later in life. When assessing the impact of child poverty on the incidence of poor health and the costs associated with poor health in economic terms, the authors took two dimensions into consideration: (1) additional expenditures on health care, and (2) the value of lost quantity and quality of life associated with early mortality and morbidity.

To determine the impact of child poverty on later health outcomes, the researchers used estimates from two studies on childhood health conducted by Case, Fertig, and Paxson (2005) and Case, Lubotsky, and Paxson (2002). To predict how child poverty affects health expenditures per age group, they used data on health expenditures prepared by the Agency for Healthcare Research and Quality (2006). Based upon their estimate that 15 percent of 4 million children are born into poverty annually, these scholars determined that poverty raises direct expenditures on health care by about $22 billion per year, and the lost “health capital” (the total value of lifetime health beginning at birth) is about $149 billion per year.
Children are not the only ones whose health care is impacted by poverty. Women living in poverty endure not only the burden of living in material scarcity but also suffer social inequalities, stigmatization, shame and humiliation, and alienation from society (Reid & Tom, 2006). As a result, they experience a sense of powerlessness to change their living conditions, a lack of autonomy and control over many crucial decisions, and a feeling of marginalization or exclusion that deprives them of participation, choices, and opportunities politically, socially, or psychologically (Burd-Sharps, Lewis, & Martins, 2008). Living under this stressful and inhospitable environment has a direct impact on their health and well being. These health difficulties are often brought on by conditions such as inadequate or unsafe housing, lack of enough “good” food, dangerous work and domestic situations, low paying jobs and extremely long work hours (Burns, Lovich, Maxwell & Shapiro, 1997; Zoller, 2005). Poverty and class are interlinked with gender (Latimer & Oberhauser, 2005; Shipler, 2004). The face of the working poor is primarily women, many of whom are divorced or unmarried with children, and who are frequently burdened with low incomes due to labor market inequities and the welfare system (Gilliom, 2001; Ruspini 2001; Shipler, 2004; Towson, 2000). Often, the stigmatization and shame of not being able to pay for medical services keeps these women from seeking even free or low cost medical screenings and subsequent treatment and follow up. In short, health care has become one way that contemporary western societies construct moral and social categories around gender, social class, sexuality, race, and ethnicity (Lupton, 1995/1997).

Latimer and Oberhauser (2005) argued that gender is an important socio-economic dimension for Appalachia women in part because of traditional gender-role
expectations, sex discrimination, educational disparities and cultural barriers in the workplace. Reid and Tom (2006) agreed:

Poor women are excluded systematically from resources and opportunities and encounter discourses that mark them as reprehensible, undeserving, and deviant. Many poor women live with shame and humiliation and are controlled by exclusionary institutions that reflect the same patterns of control and power that are often characteristic of relationships between men and women, between parents and children. (p. 403)

The majority of women living in poverty have little access to health care or little disposable income to spend on such care. Those who do work are seldom offered affordable health insurance, and even when access to insurance is available, they still cannot meet co-pays and deductibles or pay for prescribed medications. Preventative or routine medicine such as mammograms and cervical cancer screenings are luxuries. As Burd-Sharps, Lewis, and Martins (2008) explained, “the agonizing choices women often face are between paying for health care or for other basic needs, such as food, heat, and even housing” (p. 79).

Research has shown that limited access to health care services has an enormous impact on morbidity and mortality in many rural populations (see Denham, 1999; Huttlinger, Schaller-Ayers & Lawson, 2004; Katz, Wewers, Single & Paskett, 2007; McDaniel & Strauss, 2006). For example, statistics collected on chronic illness (such as heart disease and diabetes) indicate that rates are typically higher for residents of Appalachia than for residents of non-Appalachian counties (Denham, Meyer & Toborg, 2004; Latimer & Oberhauser, 2005). And the 11 counties of Appalachia Ohio served by
the CHP are characterized by some of the highest cervical cancer mortality rates in the United States (Appalachian Regional Commission, 2005; Katz et al., 2007).

The people who live in economically poor areas of Appalachia certainly understand the link between poverty and limited health care options. In the following section, I provide a historical overview of the Appalachian region and the socioeconomic difficulties encountered by those residing within its borders.

Who, What, and Where is Appalachia?

The 200,000 mile, 410 county region that comprises the Appalachian mountain system extends from the northeast United States in southern New York to northern Mississippi, encompassing all of West Virginia and parts of 12 other states, including Alabama, Georgia, Maryland, Kentucky, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee and Virginia. In October 2008, President George Bush redrew the geographic boundaries of Appalachia by adding ten additional counties in Kentucky, Ohio, Tennessee, and Virginia. By adding three new counties in Ohio (Ashtabula, Mahoning, and Trumbull), 32 of Ohio’s 88 counties are now designated as part of the Appalachian Region, and Appalachian Ohio extends all the way north to Lake Erie. Approximately 1.58 million people live in Ohio’s 32 county Appalachian region.

Although the Appalachian identity is often stereotypically exaggerated as being physically isolated and rural, its people backward, dirt-poor, uneducated hillbillies, the region is actually quite diverse in terms of geography, culture, and economic status. Not all regions are desperately poor; surprisingly, two major metropolitan areas, Pittsburgh, Pennsylvania, and Knoxville, Tennessee, are included as part of Appalachia. The
Appalachian Regional Commission also incorporates additional urban areas under its umbrella, including Birmingham, Alabama; the western fringes of the Washington, D.C., metropolitan area; the northern segment of the Atlanta, Georgia, metropolitan area; and the eastern edges of the Nashville, Tennessee, metropolitan area. There are some regions that surpass the national average in per capita income, median-household income, and median-family income; however, there are other areas which contain some of the deepest and most persistent poverty in the United States (Thorne, Tickamyer & Thorne, 2005).

“Handicapped by isolation and limited opportunities” (Tickamyer & Duncan, 1990, p. 80), Appalachia has been defined by an “uneven development of its human capital and economic resources” (Latimer & Oberhauser, 2005, p. 269). During the late 1800s and early 1900s, the abundance of coal and iron in the Appalachian Mountains provided employment for a number of Ohioans, especially those located in the eastern and southeastern parts of the state. However, once the coal had been mined, the companies pulled out and left behind a legacy of unemployment and poverty. The jobs available today in this geographic area tend to be in lower paying sectors, such as agricultural and service industries. Appalachian women living in central, rural, and distressed counties have historically had the highest poverty rates and are the most vulnerable to financial distress (Thorne et al., 2005). This is especially true in female-headed households and those which include young children (Tickamyer & Tickamyer, 1988).

With the socioeconomic conditions present, it is easy to see why health care is not often a high priority for the women living in this region. In the following section, I offer a closer look at the obstacles faced in obtaining affordable health care. From there, I move
into a discussion about how mobile health clinics are working to deliver much needed medical care for rural and marginalized populations.

*Health Care for Marginalized Populations*

The symbolic battle of how to name poverty (Burke, 1954/1984) provides unique challenges to providers and patients alike (see Prahalad 2005). Phrases such as “the poor” are overpopulated with meaning and lug their historical baggage into settings in which they are deployed. As a communication scholar, I am interested in discursive formations that shape meanings and experiences of health and healing when organized in contexts of poverty. I approach discourse from an explicitly broad perspective by casting a wide net that includes interpersonal interactions, social commentary, personal narratives, and even research that surrounds an issue across time and space. I follow the lead of Lupton (1994) who argued:

> Discourse, in this usage, can be described as a pattern of words, figures of speech, concepts, values, and symbols. A discourse is a coherent way of describing and categorizing the social and physical worlds. Discourses gather around an object, person, social group or event of interest, providing a means of “making sense” of that object, person … all discourses are textual, or expressed in texts, inter-textural, drawing upon other texts and their discourses to achieve meaning, and contextual, embedded in historical, political and cultural settings. (p. 20)

This standpoint directs attention to how discursive practices give rise to, reinscribe, and/or disrupt stigmatization. The experience of health and health care while living in poverty is hard for many people to imagine. The discourses that we encounter (and participate in) across our life spans—interpersonal interactions, institutional discourses,
public dialogues—construct hegemonic portraits of reality that naturalize the interests of the middle and upper class. Free lunch programs in elementary schools, for example, often mark participants through the use of brown colored cards instead of white cards (see Harter, Norander, & Quinlan, 2007). Such distinctions at once enable and simultaneously constrain students—the cards provide access to hot lunches even as they identify and label student as “poor.”

Stigma, then, can be understood as an ongoing, relational, and communicative process. Indeed, Goffman (1963) argued that it is productive to view stigma as “a language of relationships” through which devaluation occurs (p. 3). Individuals develop tainted identities in and through their relational encounters with others. In the case of individuals living in poverty, Duncan (1999) argued that “the poor are stigmatized, blamed for their poverty, and often deliberately blocked from the opportunities in the world of haves” (p. xiii). Yet, Harter, Edwards, McClanahan, Hopson, and Carson-Stern (2004) cautioned, a “substantial body of literature demonstrates that stereotypes regarding poverty and dependence are accepted not only by the general public, but by persons living in poverty” (p. 417). From a relational and communicative perspective, stigmatization emerges in the day-to-day activities of individuals as they relate with others in institutional and communal contexts.

The levels of poverty and despair in rural areas have often left rural people feeling stigmatized, ignored by society, angry about government bureaucracy, lacking in education, job skills and health care, and powerless and alone in their fight for survival. Yet, poverty cannot be reduced solely to the symbolic realm. Cloud (1994) offered this poignant argument:
We ought not sacrifice the notions of practical truth, bodily reality, and material oppression to the tendency to render all of the experience discursive, as if no one went hungry or died in war. To say that hunger and war are rhetorical is to state the obvious; to suggest that rhetoric is all they are is to leave critique behind. (p. 159)

Consider the following statistics: The Ohio Health Issues Poll (2007) found that the percentage of Ohioans living below the 100% federal poverty guidelines (FPG) had increased since 2005, as had the percentage living at 100-200% FPG. Demographically, those more likely to be below 100% FPG were women who were not high school graduates, who were unemployed, who lived in households with children, and who were from southeast Ohio. Additionally, people who were living below 100% FPG were more likely than other income groups to be without health insurance or to have been uninsured at some point in the past 12 months (see Table 2 for poverty guidelines).

Consider the following statistics for only Athens County: In his article on Appalachian poverty, Claussen (2000) reported that the statewide average of children living in poverty in Ohio is double in Athens County with 42 percent living in poverty, a 13 percent increase since 1990. Designating Athens County as the “poorest county in the State of Ohio,” the Department of Job and Family Services (2006) reported the poverty rate stood at 27.4% for individuals residing within the county and the number of uninsured was 7,751 people or 14.1% of county residents. According to an AP article in The Athens Messenger (2008, December 10), new census data still shows that Athens County has a poverty rate of 52.3 percent—the highest among all the cities surveyed. However, a data research analyst at Ohio University challenged these figures as he
believes the percentages in Athens County would actually be closer to 25.6 percent if the student population in off-campus housing were excluded from the survey (Higgins, 2008). No matter what the actual percentage is, the truth remains that there is still great economic hardship for many of the residents of Athens County who are not college students.

In contrast to the poverty level, however, Athens County has a relatively low unemployment rate when compared to its neighboring southeastern Appalachian counties. This data suggest that, although many people in the county are working, they are not producing adequate income to afford basic necessities, including health care. The circumstances are, instead, “producing a class of working poor” (Athens County Department of Jobs and Family Services, 2006, p. 13).

Poverty and low employment rates present financial constraints for many individuals who, as a result, lack the resources necessary to seek medical treatment. To help understand the underlying or root causes of women’s poor health, Burns et al. (1997) posited that women, as a group, are treated differently from men in that they usually have less power and fewer resources, have a lower status in the family and community, suffer more frequently from poverty, are denied the education and skills to support themselves, lack access to important health information and services, and lack control over their basic health care decisions. These are communicative as well as material challenges. Culture also plays a significant part in the outcome of medical care for marginalized populations such as those living in Appalachia. As Charon (2006) noted:

Matters of belief as well as fact, ideas about the causes and cures of disease run deep in one’s culture, religion, and family. …. Doctors might be convinced about
the cause of a disease only by replicable scientific evidence, while patients may be swayed in their beliefs about etiology by faith, culture, family lore, and mythic/magical notions of human biology. (p. 28)

Issues of geographic remoteness and limited transportation options further compound barriers to obtaining health care (see Denham et al., 2004; Pistella, Bonati, & Mihalic, 1999). Other barriers to care include an uneven distribution of physicians among geographic areas and disparities in the availability of health care services (McKinley, 2005) and limited contact with physicians and preventive care and fewer community services (Katz et al., 2007). The social and cultural environment (norms, cohesion, values, and networks) also come into play (Katz et al., 2007) as “strong values for place, connection to family, and importance of religion are important themes related to health and illness needs of many residents in this region” (Denham et al., 2004, p. 171). While you and I might take for granted that we have a family physician, for those living in poverty, having a doctor is often a sign of social status and social inclusion. However, for many Appalachians the strong distrust of outsiders and a reluctance to seek help outside their familial setting often deters finding needed medical care. In short, discursive, geographic, and material forces can work to separate those living in poverty in Appalachia from mainstream medicine.

Providing Health Care Through Mobile Clinics

While discussing disruptive innovation for social change, Christensen, Baumann, Ruggles, and Sadtler (2006) called for “catalytic innovations” in health care. Catalytic innovations, such as the Minneapolis-based Minute-Clinics which provide patients with fast, affordable, walk-in diagnosis and treatment, challenge the status quo by approaching
health care in new ways through creating scalable, sustainable, systems-changing solutions which offer “simpler, good-enough alternatives” to an underserved population (Christensen et al., p. 96). Through their alternative way of organizing health care resources for traditionally underserved populations, mobile clinics also provide one such catalytic innovation. The clinics have the potential to enhance access into the medical care system (Edgerley, El-Sayed, Druzin, Kiernan, & Daniels, 2007) and to help break down barriers by providing either free or low cost medical care. The ability to take health care on the road to people in need not only alleviates financial barriers but also helps to break down the barriers of geographic isolation, helps fill the void created by a lack of physicians, alleviates the need to miss work or school for doctor’s appointments, and offers a solution for the lack of patient transportation.

In their study of underserved and rural women using mobile health clinics for prenatal care Edgerley et al. (2007) and Pistella, Bonati, and Mihalic (1995) found that these women initiated care as much as three weeks earlier than women initiating care at other community health clinics. McDaniel and Strauss (2006) determined that many clients preferred the family atmosphere of the mobile clinic over more structured and traditional health care settings. Besides providing affordable and convenient care, the mobile clinics, held near a participant’s residence or his/her children’s school, reduced transportation barriers and made child care more readily available.

Mobile clinics have emerged in recent years to address a number of health care needs for the underserved and marginalized, including mammography screenings (Derose, Duan, & Fox, 2002), the identification and treatment of sexually transmitted diseases (Liebman, Lamberti, & Altice, 2002), osteoporosis (Newman, Olenginski,
Perruquet, Hummel, Indeck, & Wood, 2004), a needle-exchange delivery system among high-risk patients (Pollack, Khoshnood, Blankenship, & Altice, 2002), and HIV and AIDS (Zebus & Trinh, 2001). The mobile health clinic in this current study provides free medical clinics, performs breast and cervical cancer exams, administers childhood and adult immunizations, and conducts healthy adult screenings throughout the rural communities of Appalachia that they serve.

Formed in 1996 and serving 21 Ohio counties (11 of which are considered Appalachian), the Community Service Programs (renamed Community Health Programs in 2006) grew out of the Childhood Immunization Program (CHIP). Originally working out of one 40-foot van, the Community Health Program (CHP) staff soon realized that there were many other unmet health needs that existed in their service areas, and as a result, a second mobile unit was added in 2001. With this second mobile unit in place, medical services were expanded to include the Healthy Adult Project (HAP), which provides blood pressure, glucose and cholesterol screenings and referrals for adults, along with breast and cervical screenings and education for women.

While the CHP now offers a free medical clinic, immunizations, and breast and cervical cancer screenings at a fixed location on a limited basis, most of their clinics are conducted in the two mobile units which are set up at various outreach sites throughout their service area. Last year, the mobile unit traveled 12,900 miles and provided over $714,000 in free clinical services to uninsured patients in southeastern Ohio alone (Today’s D.O., 2007). The program recently received a two-year $50,000 grant from the Sisters of Saint Joseph Charitable Fund to help expand free medical services into Meigs and Washington counties. To be eligible for these grant-funded services, patients must be
18-64 years old, uninsured, and live at or below 150% poverty level for the free clinics and at 200% of the poverty level for the Ohio breast and cervical clinic program (see Table 2).

The outreach sites used by the units vary by location and include parking lots of local hospitals, community or senior citizens’ centers, local elementary schools, local grocery stores or even gas stations. When serving especially rural or Amish communities, it would not be unusual to find a mobile unit parked in a field or in a farmer’s driveway. Often, the mobile staff will supplement the limited space inside the unit by using space inside a community health department or another near-by facility such as an elementary school.

The primary CHP staff consists of one director, one administrative assistant, one full-time and two part-time van drivers, one nurse practitioner, one certified medical assistant, six registered nurses, and one or two occasional rotating physicians (primarily at the monthly free clinic). Often osteopathic medical students will observe and assist the nurse practitioner during mobile clinics.

The CHP program also administers a perinatal education program and their perinatal educator works on site at a local OB/GYN practice with patients who are at high-risk for pre-term labor. Additional medical services offered by the mobile clinic include bus driver and athletic physicals, a well-child and well-family program for pregnant women and children, and a referral system for other needed services such as mammograms.

The very process of operating a mobile clinic lends itself to efficiently serving its patients. For example, mobile clinics have the ability to set up shop quickly and in
virtually any location, function with minimal staffing and overhead, and administer a variety of health care services and screenings quickly so patient wait time is minimal. By bringing health care to the doorsteps of its patients, the mobile clinic reduces barriers exacerbated by the lack of available and affordable transportation and lessens the need for patients to take large chunks of time off from work in order to receive care.

Even so, there are also a number of challenges associated with these clinics. The mobile staff is frequently required to go to great lengths to assure that there is a continuity of care provided amidst constantly shifting scenes such as the locale and location of the clinics. There are also challenges presented by inadequate, reduced or lost grant funding, and it is not unusual, for example, for the breast and cervical staff to suspend screening through the summer months while waiting for the next fiscal year’s grant funding to begin.

Due to financial constraints, it is often difficult to find physicians or facilities with sliding fee scales or who will take referrals for patients who cannot pay. One breast and cervical screening patient in a nearby county disclosed to staff that a local for-profit hospital would not accept payment vouchers to perform mammograms on patients who had outstanding bills from previous visits. This dilemma is magnified when patients have medical conditions that require the care of a specialist or frequent follow-up appointments (McDaniel & Strauss, 2006).

Other challenges faced by the clinics arise from the very essence of being mobile—mechanical problems with the van or generator, medical equipment malfunctions, inclement weather (either for traveling or for patients who might have to wait in line outside the van), a limited number of staff to care for patients and limited
space on board to accommodate those patients. Clinics in rural areas present challenges such as a lack of cell phone service for calling providers to schedule follow-up screenings for mammograms or other diagnostic services while patients are waiting. The clinic staff is also beginning to face language barriers as they encounter more and more non-English speaking patients.

As I know from personal experience, people living in poverty are proud people who do not like to take handouts. Many of the people who need the services of the mobile health clinic will not come because of the stigma and shame associated with being poor and subsequently needing free medical care. For example, Duncan (1965) drew on Burke’s argument that people who are poor are often labeled as “lazy, degenerate, shiftless, sick, evil, childlike, cunning, ignorant, proud, humble, victimized, and unfortunate” (p. xv).

I believe that the issues of stigmatization (Goffman, 1963), identification and consubstantiality (Burke, 1969) in the mobile clinic are not separate, but are part and parcel of the whole. The CHP staff often uses personal stories to establish identification and create a bond with their patients and to help soften the stigma associated with using the free services so they do not feel threatened or ashamed. Many times, this sharing of stories opens up a reciprocal dialogic thread that allows medical personnel to dig deeper into the root cause(s) of their patient’s illness or health issues. In the following chapters, I develop a theoretical and practical rationale for exploring how creating a sense of identification and consubstantiality with patients facilitates care giving, and how creating a space for shared illness and health stories provides a mechanism for healing and empowerment.
Summary

Through an interpretive case study of the OUCOM mobile health clinic, this dissertation represents my attempt to explore alternative ways of organizing health care resources for underserved populations. Providing health care to underserved populations is a complex issue about which there has been no shortage of scholarly discussion. However, I leave most academic discussions desiring deeper explorations of how symbolic forces intersect with corporeal, material, political, and institutional conditions to shape people’s experiences. Symbolic forces of any kind, including narratives, construct relationships among people, events, objects, and institutions. In particular, I am committed to identifying symbolic and extra-symbolic forces that coalesce in ways that allow women and children to be resilient in the face of inhospitable conditions as they gain access to telling stories of their health in more empowering ways.

My journey as a co-constructor of meaning about the experience of health and health care in OUCOM’s mobile clinic demanded scholarly entry points. As discussed earlier, I approached the organizing of health care resources from a discursive standpoint. Communication scholars regularly assert that organizations, professions, and labor itself is both medium and outcome of discourses (e.g., Fairhurst & Putnam, 2004). Participants in mobile health clinics draw on communicative rules and resources to enact their roles; at the same time, these resources are the means of system (re)production. A primary discursive resource that remains the coin and currency of organization are narratives. Indeed, twenty years ago, Mumby (1987) asserted that narratives are the principal symbolic form through which organizational structures, policies, ideologies, myths, rituals, and routines are (re)produced and resisted:
Narratives do not simply inform organization members about the values, practices, and traditions to which their organization is committed. Rather, they help to constitute the organizational consciousness of social actors by articulating and embodying a particular reality, and subordinating or devaluing other modes of “organizational rationality.” (p. 125)

Because of narratives’ sense-making capacities, organizational members rely on storytelling to bring (dis)order and meaning to collective life.

Providers themselves are beginning to recognize that the organization and provision of health care would be impossible were it not for our human capacity to embody lived experience in narrative form (e.g., Charon, 2006; Greenhalgh & Hurwitz, 1998; Montgomery, 2006). Providers draw on their narrative competence (i.e., their ability to enter into the stories of patients) as well as scientific information and clinical research when they exercise clinical judgment. In short, providers are challenged to read physical symptoms normatively—in the context of a patient’s life and in light of biomedical stories. The mobile health clinic offered a unique opportunity to empirically enrich narrative literature by exploring the storied nature of health and health care amidst ever-shifting scenes of activity. At the same time, communication scholarship implicitly assumes a monolithic orientation to the contexts of care (i.e., primary care physicians’ offices, hospitals). Through this study, I extend the communication discipline’s theoretical and practical reach to include alternative forms (i.e., outside primary care physicians’ offices, hospitals) of organizing health care resources.

The following chapter more fully articulates my theoretical standpoint that serves as the philosophical backdrop for this dissertation. I situate my narrative orientation
amidst a growing body of inter-disciplinary literature focused on narratives, health, and healing.
CHAPTER 2: THEORETICAL STANDPOINT

During the process of writing this dissertation, I had the opportunity to experience and reflect upon how illness narratives help to navigate and make sense of frightening and uncertain health experiences. One of my students, a 19-year old female, had recently been diagnosed with malignant melanoma. When she had surgery to remove the cancerous mole on her forearm, the cancer was so deep that the doctor had to remove the tissue clear down to the tendon. The doctor also had to remove two cancerous lymph nodes from her left breast. When her post-operative test results came back, she still had cancerous lymph nodes/cells in her breast tissue. She soon began a schedule of chemotherapy to hopefully eradicate the remaining cancer cells.

As I talked with her sobbing and grieving mother for over an hour this particular morning, I found out that the student initially did not want anyone to know her story for fear of pity. We talked about how the doctor told mom that this was not her fight and that her daughter had to take charge of her treatment regimen. We talked about how her daughter had begun witnessing (Frank, 1995, would call this a restitution narrative) to others about the dangers of tanning beds by placing photos of her gruesome-looking forearm on Facebook for her peers to see. We talked about my oldest sister’s recent bout with Stage 3 breast cancer and how our lived experiences now included a world that revolved around the next chemo treatment and the next radiation treatment—all the while waiting to hear whether the pain and sickness had been in vain or whether the cancer had been beaten back. The mom and I talked of caring and strength and support and love.
We talked of hope—hope that a 19-year old basketball star athlete could conquer cancer with her otherwise healthy and fit body.

As we talked, I could not help thinking "This is what the storied nature of health and illness is about. This is what gives narrative the strength and body to speak to people, to help people heal from whatever life has thrown at them. This is how telling our lived experiences of victory over illness helps others gather strength and hope to fight their own battles. This is how we work to construct the self in order to provide meaning and understanding to our health experiences."

Personal and group narratives “assert both a right to proclaim publicly one’s identity and the need to define one’s experience as relevant” (Harter, Japp, & Beck, 2005, p. 24). The stories we tell have been shaped by, and in turn shape, our standpoints which are always “unfinalizable and capable to outgrow” (Bakhtin, 1984, p. 59). Our standpoints, as a result, hold a key for making sense of our lives and those of others.

In this chapter, I articulate my theoretical standpoint—a position that has developed as a result of my encounter with cherished theories of the communication discipline or what Somers (1994) called “canonical stories.” At the same time, my personal experiences continue to influence how I make sense of the work of Burke, Goffman, Foucault, and others even as these philosophers have prompted ongoing self-reflexivity.

Among the multiple identities which have informed my theoretical standpoint are wife, mother, college student, educator, feminist, and musician. The experiences that cemented my interest in this dissertation topic bubble up from my lived experiences as a poor, medically deprived, female child of Appalachia. Although I cannot escape the
narrative standpoint of my upbringing, my personal pain of stigma and poverty, I can use my knowledge and my lived experiences to create a space for those who often remain invisible to narrate their lives—particularly how they experience health and healing. Stories are relationships that entail becoming more aware of, and more reflexive about, our own standpoint as we are exposed to the standpoints of others (Frank, 2002). Narratives provide the space and “a powerful medium for learning and gaining understanding about others by affording a context for insights into what one has not personally experienced” (Garro & Mattingly, 2000, p. 1). I care deeply about the patients and families served by OUCOM’s mobile clinic—I have walked in similar shoes—I am one of them.

Standpoints, then, reflect “self-consciousness about how the fate and choices in your life have positioned you in the world and with whom you have been positioned” (Frank, 2000, p. 356). I begin this chapter with an overview of my narrative sensibilities and position my standpoint within the broader discipline. I then explore several defining aspects of narrative theory including its ability to explore identity construction, the organizing of our relational and communal lives, and health and health care. Finally, I offer general research questions that will guide my dissertation.

Defining Features of Narrative Theory and Practice

Narrative is the primary form by which humans give meaning to their experiences by organizing these experiences into meaningful episodes (Polkinghorne, 1988; Richardson, 1995). Comprised of organizing themes or “plots” that identify the significance and contribution that individual events make to the development and outcome of our stories, narratives contain a temporal and spatiotemporal dimension that
helps us situate our stories in time and space. The perceived coherence of the temporal order of narrative events determines the plot and, subsequently, the power of the narrative as a story (Czarniawska, 1998). Ricoeur (1984b) hypothesized that time becomes human as it is articulated through narrative, and concomitantly, narrative attains its full meaning when it becomes a condition of temporal experience. Feminist researcher Laurel Richardson (1990) aptly describes the temporality of narratives as follows:

Narrative gives room for the expression of our individual and shared fates, our personal and communal worlds. Narrative permits the individual, the society, or the group to explain its experiences of temporality because narrative attends to and grows out of temporality. It is the universal way in which humans accommodate to finitude. Narrative is the best way to understand human experience and hence the least falsifying of that experience. (p. 218)

Narratives provide relevance, context, and connectedness (Bateson, 1979) and they help us situate ourselves in the world (Bochner, 2002), help us organize our understandings of the world (Cortazzi, 2001), help us understand the meaning of our lives by teaching us where we come from and where we are going (Charon, 2006), and they create and re-create selfhood (Bruner, 2002). Narratives bring stories to life in a way that few other methods do by connecting and reconnecting the elements and making those elements move in such a way as to inspire personal action. Through narratives we make sense of the world and of our relationship to that world and between ourselves and others. Narratives reflect and shape the interpretations of self and help us produce and negotiate our identities (Weick, 1995).
“Narrative meaning is created by noting that something is a part of some whole and that something is the cause of something else” (Polkinghorne, 1988, p. 6). And, through both its ordering and disordering impulses “narrative can help one see newly and for the first time something concealed, something overlaid, something buried in code” (Charon, 2006, p. 219).

According to Fisher (1984), the basis of the narrative paradigm centers around the premise that humans are essentially story-telling animals, that communication is best viewed as stories that have been shaped by our history, culture and character, and that “values, emotions, and aesthetic considerations ground our beliefs and behaviors” (p. 2). In other words, “we are more persuaded by a good story than a good argument” (West & Turner, 2000, p. 290).

Fisher further argued that, as narrative beings, people retain their everyday information as anecdotal narratives with characters, plots, motivations and actions. He asserted that we evaluate stories in two ways—narrative probability (what makes a story coherent) and narrative fidelity (does a story speak to our real experiences). Fisher contended that narrative is intertextual in nature as one’s life is “a story that participates in the stories of those who have lived, who live now, and who will live in the future” (p. 6).

Goffman (1959), too, suggested that we situate ourselves normatively through the use of scenes, scripts, frontstage, backstage, and performances. Performance as defined by Goffman includes “all the activity of a given participant on a given occasion which serves to influence in any way any of the other participants” (p. 15). The frontstage, which consists of the setting (furniture, physical space, etc.), is where a performance
takes place. The backstage, which houses the items of the personal front (clothes, gender, race, age, etc.), is an area located away from the audience. Goffman noted, however, that “there are many regions which function at one time and in one sense as a front region and at another time and in another sense as a back region” (p. 126). During the scenes that make up the performances of our narrative scripts, we slip back and forth between an often negotiated and shifting front and back stage (see also Ellingson, 2005). While recognizing that there is fluidity to our stories, Goffman also believed that these stories play out in rituals and regularities and particular scenes come to take on different meanings at different times in different contexts.

Each of us develops a small number of scripts from which we choose to narrate the scenes our lives. Scripts are co-created by participants and become institutionalized through communication (Goffman, 1959). Sometimes these scripts create “trained incapacities” (see Burke, 1954/1984) that lead individuals to repeat the same scenes over and over again (for example, convicted felons might repeat the same crimes and keep being sentenced to prison; victims of domestic abuse might keep going back to their abusers). The concept of trained incapacities can also help us understand one way stereotypes take root (for example, women and children living in poverty and in a culture that devalues them may keep repeating often destructive patterns generation after generation).

Narration, communication rooted in time and space, covers diverse aspects of our lives and the lives of others in regard to character, motive, and action. Embedded in our ongoing stories, and disruptive by its very nature (Charon, 2006), narrative invites listeners to interpret its meanings and assess its value for their own lives (Griffin, 2006).
Narratives can be empowering, chaotic, unpredictable, therapeutic and disruptive, often simultaneously, whether a story is at its beginning, middle, or end. Bochner (2002) stressed that “we must heed the call to stories in order to understand how people make sense of their experiences, how they wrestle with the difficulties of attaching meanings to events under the press of human contingency and uncertainty” (p. 73). Mason (2004) called narratives “interpretive devices through which people represent themselves to themselves and to others and a means by which people connect past and present, self and other” (p. 165).

Narratives allow us to rethink and remember our lived experiences as bases of knowledge (Polkinghorne, 1988), size up situations in various ways, craft livable truths, and offer frameworks for possible worlds (Bruner, 1986) while remaining as fluid as the people or societal practices that they reproduce and/or resist (Burke 1937/1984). Narratives can change people’s lives (Frank, 1993) and often bring about dialogue, understanding, and connections that might not otherwise occur. Narrative acts help build community (Charon, 2006; Clair, 2006), and they help us claim identities, repair our damaged identities (Lindemann-Nelson, 2001; Trethewey, 2001), construct our lives, structure perceptual experience and organize memory. What actually gets included and excluded in this narrativization, how events are plotted, and what these events are supposed to mean are guided by human agency and our imagination (Riessman, 1993).

Somers (1994) defined narrative and narrativity as concepts of social epistemology and social ontology and claimed that social life is stodied and narrative is an ontological condition of social life (emphasis in original). This means that we come to know, understand, and make sense of the social world and constitute our social identities
through narratives and narrativity. As Somers explained, “The chief characteristic of narrative is that it renders understanding only by connecting parts to a constructed configuration or a social network of relationships composed of symbolic, institutional, and material practices” (p. 616).

Burke (1941/1967) maintained that literature serves as “equipment for living” that offers wisdom and common sense to people and helps guide the way they live. Narratives can also be described as equipment for living since humans structure their experiences narratively as stories and/or dramas. Our narratives act as a sensemaking tool for self and other as they are created and create social interactions. Much like the who, what, when, where, and why of journalistic inquiry and storytelling, narrative theorizing generally draws our attention to relationships between scenes, acts, agents, agency, and purpose while providing a rich and enlightening perspective for how and why context matters (Burke, 1954/1984).

Through their symbolic nature, narratives sustain cultures and pass from generation to generation. One example of narratives that have passed from generation to generation and that are present in many cultures is fairy or folk tales. Both children and adults use these types of narratives (themes and metaphors) to explain and to make sense of a variety of happenings in their daily lives.

Narratives have been used throughout the centuries to rebel against social constraints, to convey points of view about social norms, to serve as an oral history (with various alterations in the course of retellings), to understand societal and literary references, and to offer moralistic lessons (Deardorff, 1999). They have also been used as entertainment, as parables, and as warnings in an attempt to influence a listener’s
behavior. Scholars have argued that fairy tale narratives function in society as a paradigm for understanding the community and other cultures (Rohrich, 1986) and, as such, help individuals determine how to behave within that community (Bettelheim, 1975).

The “once upon a time” and “they lived happily ever after” structure of fairy tales, Riessman (1993) argued, give listeners a sense of the beginning, middle, and end of the narrative. She further argued, however, that stories told in other settings are rarely that clearly bounded, and the interpretive process is often more difficult, and “where one chooses to begin and end a narrative can profoundly alter its shape and meaning” (p. 18).

In addition to the “telling stories,” such as fairy tales, family myths, parables, legends, and traditions, narrative takes shape in a variety of genres including texts such as novels, newspaper stories, scripture, movies and music, and in our daily life settings such as courtrooms, battlefields, marriages, and illnesses (Charon, 2006). We use our narrative knowledge to make sense of these stories, to understand events befalling other individuals, and to help understand situations as they unfold in time. Riessman (1993) asserted that we recognize a genre by the presence of specific conventional elements—habitual narratives (events happen repeatedly resulting with no peaks in the action), hypothetical narratives (depicts events that did not happen), and topic-centered narratives (thematic linking of snapshots of past events).

Although different genres of narrative persuade differently, their influence and efficacy as a sensemaking tool (narrating as emplotment to construct significant networks or relationships) cuts across socioeconomic boundaries, race, gender, and culture. Just as beauty is in the eye of the beholder, narrative meaning resides in the viewer—the narrative meaning is what we choose to make of it based on our lived experiences. The
basic fundamental aspects of living such as “recognizing self and other, connecting with traditions, finding meaning in events, celebrating relationships, and maintaining contact with other are accomplished with the benefit of narrative” (Charon, 2006, p. vii).

Scholars, too, try to co-construct, interpret and relate stories of lived experiences in such a way that the rest of us will be prompted to pay heed and to keep in mind how it goes for “others.” Riessman (1993) argued that the interpretation of our stories is inevitable because narratives are representations. Narrative storytelling “draws its strength from ordinary people whose lives are brought directly to the reader through remarks made, questions answered, memories shared, experiences told” (Duncan, 1999, p. ix). And, as Frank (1993) argued, “Published narratives carry the implicit promise that a new identity is available to others undergoing the same epiphanal experiences, and possibly available even to those who have not” (p. 42).

Charon (2006) summarized the relevance and efficacy of narrative theory when she argued:

A narrative shift has taken place across many fields of human learning, such as anthropology, history, psychology, social science, law, and mathematics, challenging scholars and practitioners from religious studies to psychoanalysis to police work to concentrate on not just the facts but the situations in which these facts are told. Narrative knowledge and practice are what human beings use to communicate to one another about events or states of affairs and are, as such, a major source of both identity and community. (p. 11)

Now that I have given an overview explicating what narratives bring to our every-day table, it seems that there are a number of questions begging for further discussion.
Why are we so interested in narratives and the process of narrating—in telling the stories of our lived experiences and hearing about the lived experiences of others? Why do we tell a story the way we tell a story? Why do autobiographical stories such as Frank McCourt’s (1996) Pulitzer Prize winning *Angela’s Ashes: A Memoir* or Maya Angelou’s *I Know Why the Caged Bird Sings* (1997) resonate with millions of people? What is it about these stories that inform our own stories?

In the following section, I delve deeper into how narratives construct our identities through their autobiographical performances and how these autobiographical performances impact our lives. Then, I move into a discussion of organizational narratives and how they facilitate organizational culture, reinscribe power relations, and serve to structure lived experiences for members within an organization. Lastly, I examine how personal, organizational, and public narratives blur and are intertextually woven because of their robustness and boundary-spanning nature.

*Autobiographical Performances of Narratives*

Autobiographical narratives are an organizing principle of our lives and they serve as a lens through which we filter our experiences and make action plans for our lives (Lindemann-Nelson, 2001), and they structure perceptual experience and organize memory. Langellier (1999) asserted that personal narrative is emergent because each performance is unique and is based upon the particular circumstances (time, space, scripts, meta-narratives, culture, etc.) of the participants involved in the performance(s).

Personal stories are the building blocks of personal knowledge because our identities are constructed through self, other, and the world (Beck, 2005). These narratives also serve as a boundary or connection between literary and social discourse,
between written and oral communication, between public and private spheres, between ritual performance and incidental conversation, and between fact and fiction (Langellier, 1999).

Our narrative inquiry inspires participation and involvement and promotes the inclusion of multiple voices, encourages dialogue, and attempts to keep a conversation going (Bochner, 2002). According to Riessman (1993), “individuals become the autobiographical narratives by which they tell about their lives” (p. 2); they recapitulate and reinterpret their lives through storytelling (p. vi).

Autobiographical performances, either our own or those with whom we have contact, have potential role modeling effects. Holstein and Gubrium (2000) determined that the meaning and coherence of a story and of the self it conveys are drawn from the linkages built between autobiographical performances (personal and biographical accounts) and the contextualizing of who and what we are. These role modeling effects can have a particularly significant impact for marginalized groups such as women and minorities as “there is considerable narrative play at work in the way shared understandings about power, success, and discrimination are brought to bear on matters of self definition” (p. 108).

Our identities are evolving constructions which emerge out of continual social interactions in the course of life (Scheibe, 1986). An ongoing process of social action (Cobb, 1993; Gergen, 1994) and a potential resource of negotiated identity construction (Ainsworth & Hardy, 2004), narratives operate as a form of social action that assists in producing the identities of ourselves and others. It is through the narrative process that identity amid a myriad of constituencies can be contextualized. Stories guide action and
people construct identities (however multiple and changing) by locating themselves or being located within a repertoire of emplotted stories.

Lindemann-Nelson (2001) argued that personal identity, the interaction of one’s own sense of self and others’ understanding of whom one is, functions as a lever that expands or contracts one’s ability to exercise moral agency. When telling stories, “participants not only convey their individual points of view, they also stake claims to, and invite others, to inhabit moral communities” (Ryfe, 2006, p. 80). Narratives help us know by cultivating our moral emotions and refining our moral perception; they teach us our responsibilities; they motivate, guide, and justify our actions; through them, we redefine ourselves (Lindemann-Nelson, 2001). Telling narratives helps individuals make sense of disruptive events in their lives; stories pull the listener into the teller’s point of view (Riessman, 1990). Often, knowing is interrupted or realigned through the use of narratives.

The way we are treated or the way we treat others within a particular social group is often facilitated through the identities that we construct or that others construct of us. For example, those who live in poverty are sometimes treated by those in more powerful positions (physicians, social service providers, educators) as being unworthy of their respect and, as a result, they are often denied the same type of medical treatment or quality of living or instruction as the people with whom they interact. This type of social isolation, which is brought about by stories which mark us as candidates for certain treatments over others, often leads to the experience Lindemann-Nelson (2001) called “damaged identities.”
Although our identities are both narratively constituted and narratively damaged, Lindemann-Nelson asserted they could be repaired through the use of counterstories. Counterstories, she explained, are designed to resist the evil of diminished moral agency. They aim to alter the dominant group’s perception of the subgroup and to alter the person’s self-perception. Counterstories resist master narratives (the stock plots and stories that summarize socially and culturally shared understandings) by uprooting and replacing them with a better alternative. Lindemann-Nelson further explained how counterstories work to repair damaged identities:

Counterstories, then, are tools designed to repair the damage inflicted on identities by abusive power systems. They are purposive acts of moral definition, developed on one’s own behalf or on behalf of others. They set out to resist, to varying degrees, the stories that identify certain groups of people as targets of ill treatment. Their aim is to re-identify such people as competent members of the moral community and in doing so to enable their moral agency. (p. xiii)

Personal narrative, narrative performances, and counterstories are important in establishing, reinventing, maintaining, and disrupting organizational cultures. In the following section, I discuss how narratives operate within organizational structures and offer examples of ways in which organizations and the people within them have used narratives to draw attention to an underserved and/or marginalized population, to establish institutional identity and values, to build community and loyalty, to introduce change, and to evoke social change and social justice.
Organizational Cultures

The study of narratives in organizational contexts has covered a myriad of topics, including sense making and organizational socialization (Boje, 1991; Brown, 1987; Davis, 2005), the framing of sexual harassment experiences (Clair, Chapman, & Kunkel, 1996; Wood, 1992), the role of organizational narratives in expressing and constituting organizational ideology and power (Clair, 1993; Mumby, 1987), in forming institutional identity (Czarniawska, 1997), in community building within small groups (Froggett & Chamberlayne, 2004; Ryfe, 2006), in counterstories of disability and poverty (Harter, Edwards, McClanahan, Hopson, and Carson-Stern, 2004; Harter, Scott, Novak, Leeman & Morris, 2006), in constructing shared group identity (Kitchell, Hannan, & Kempton, 2000), and in reproducing social order (Meyer, 1995; Peelo & Soothill, 2000).

Organizational narratives serve to structure lived experiences for members within the organization because storytelling is woven into the very fabric of organizational culture. Narratives provide the foundation for reality construction (Brown, 1987) and play the role of symbolic creators and “function as communications of shared systems of meaning that allow organizations, as speech communities, to make sense of their environment” (Myrsiades, 1987, p. 90). Narratives serve to inform members not only about the history, mission, goals, values, practices, and traditions of their organizations (Davis, 2005), but also help to “constitute the organizational consciousness of social actors by articulating and embodying a particular reality” (Mumby, 1987, p. 125). Additionally, members use stories in the socialization process and as a means to express their knowledge, understanding, loyalty, and commitment to the organization (Brown, 1985).
Stories can enable or constrain a member’s behavior, and they can set the standards by which social practices are considered appropriate or inappropriate within an organization (Meyer, 1995). Organizational narratives promote organizational reflexivity, act as a vehicle through which members can offer definitions and explanations of their work life, serve as a concrete, memorable, and persuasive communication format. They can be used as evidence establishing the need for change and as a tool for measuring changes in organizational policy, behavior, or structure (Brown & Kreps, 1993/2001). Members reflect and reproduce an organization’s corporate culture through the stories that are constructed. Furthermore, these stories provide the material from which new organizational life stories can be created (Barge, 2004).

Pacanowsky and O’Donnell-Trujillo (1983) identified three types of narratives that occur within organizations: personal stories, collegial stories, and corporate stories. Although often privileging the lived experiences of some members over those of others, these stories provide memorable experiences for an organization while “providing members a vehicle for dramatizing organizational life” (p. 177). Organizational members often use personal stories as a way of bragging about themselves or as a way to proclaim their superior prowess or skill over other organizational members (for example, a firefighter claims she is invincible or a policeman claims he is tougher than any criminal). Collegial stories, typically not recognized or encouraged by management, are narratives that individuals share about others within the organization. These stories, which range from amusing anecdotes to employment matters, describe the underlying way the organization really works. Corporate stories are encouraged by management to
substantiate organizational rules and regulated procedures and to pass on unwritten but favored customs of the organization.

Organizational structure, which is both the medium and the outcome of members’ social practices (Giddens, 1979), is partially shaped by the narrative fabric of a particular organization. Narratives evolve as a product of certain power structures, they function ideologically to produce, maintain, and reproduce those organizational power structures, and they are an integral part of deep structure (i.e. master narratives) and rationality (Mumby, 1987). As Mumby explained, “Narratives provide members with accounts of the process of organizing. Such accounts potentially legitimate dominant forms of organizational reality, and lead to discursive closure in the sense of restricting the interpretations and meanings that can be attached to organizational activity” (p. 113).

Narratives, however, can also delegitimize dominant meaning systems leading to what Giddens (1979) called a “dialectic of control” whereby the subordinate or powerless members use the organizational structure to their advantage.

The habitual use of organizational storytelling suggests that power is available and diffused by those who can speak the ideology of the organization (Mintzberg, 1983). Although organizational stories often appear in written forms (for example, a vision or goals statement), these stories function predominantly through the individual interpretations and reconstructions of the organizations’ members (Polkinghorne, 1988). Our storied interpretations of organizational narratives can call into question the consequences of the institutions we have inherited, and can give credibility to alternative realities around which to organize (Harter, Norander & Quinlan, 2007).
Goffman’s (1959) metaphor of performance (frontstage, backstage, scripts, and scenes) suggests that theatricality and play-acting are part and parcel of narrative talk within organizational communication. His notion of performance implies that some organizational performances are overdone (for example, the vice president of a company overturns furniture in reaction to a new accounting procedure) and that all organizational performances might be suspected as being displays of role-distancing and presentations of organizationally-required masks (for example, an individual is a tyrant at work but recognized as a nice neighbor in the community). As Goffman maintained, “All the world is not, of course, a stage, but the crucial ways in which it isn’t are not easy to specify” (72).

Boje (2001) offered a different take on how organizational narratives are scripted and performed. His proposed “antenarrative” takes into account that stories and storytelling is fragmented, nonlinear, and collective in nature—stories exist in a world of multiplicity and travel from place to place, often bumping into one another. Boje argued that antenarrative precedes narrative, and depending on the often conflicting tellings and multiple interpretations of the same happening, antenarrative is where the forecasting of sensemaking occurs. As Boje explained,

Antenarrative gives attention to the speculative, the ambiguity of sensemaking and guessing as to what is happening in the flow of experience. It answers the question, “what is going on here?” Antenarrative is constituted out of the flow of lived experience, while narrative method is more meta; it is about the storytelling that came before. (p. 3)
The premise of the antenarrative, which can also be applicable outside the organizational narrative realm, will be addressed further in the section on the storied nature of health care when I examine how stories of sickness are constructed within the multiple registers of the body.

Personal and autobiographical narratives more often than not bleed over into our interactions with, and our immersion within, the organizations with whom we are affiliated. Moreover, our personal and organizational narratives cannot help but to spill over into the public arena as well since our stories and lived experiences provide an interface or bridge between and among these different and sometimes contested terrains. As Goodall (2000) explained, story-telling episodes are forms of disclosure used “to situate, coordinate, detail, and explain or retell pivotal events in a personal or organizational life” (p. 104). In the following section, I offer insight into how this blending or blurring crosses boundaries and, concomitantly, how these occurrences impact the knowledge, dialogue, and understanding of those involved.

*Individuals, Organizations, and Public Interface*

Narratives are never solely personal, organizational, or public in their telling. Instead, “stories necessarily bleed across the artificial boundaries of discrete areas of knowledge” (Harter, Japp, & Beck, 2005, p. 93). Narrative, in all its forms, is a dialectic between the contexts of what is expected to occur and what actually happened; narratives are instruments not just for solving problems, but for finding problems as well (Bruner, 2002). Meaning emerges not from the act or thoughts of any single person, but from the interfaces between people, between stories, and between contexts. As Goffman (1959)
suggested, “Scripts even in the hands of unpracticed players can come to life because life itself is a dramatically enacted thing” (p. 72).

Personal narratives often become the building blocks of both public and institutional knowledge as the people who make up the entities share their lived experiences via dialogue with others. Individual narrative identity is developed in interaction with its social and cultural contexts (Bruner, 1990; Good, 1994), and Kirkman (2001) explained the blurring of narrative boundaries in this way:

An autobiographical narrative can be classified as public because it is the result of negotiation with groups beyond the private sphere of family and intimate friends. It also can be called public because it is presented to a public audience. These two (development and presentation) are intrinsically enmeshed. (p. 530)

Our dialogue with others will take place in some mode, be it confirmation, denial, or challenge. Bakhtin (1981) aptly described this ubiquitous and boundary spanning nature of narrative:

The living utterance, having taken meaning and shape at a particular historical moment in a socially specific environment, cannot fail to brush up against thousands of living dialogic threads, woven by socio-ideological consciousness around the given object of an utterance; it cannot fail to become an active participant in social dialogue. (p. 276)

Bakhtin’s notion of dialogic threads is an important element in understanding the intertextual relationship between personal stories, organizational scripts, and societal dramas. The robustness of narrative theory does not simply lie in the practice of storytelling alone; it is the intertextual weaving of the dialogic threads of storytelling that
allows narrative to be a brilliant vessel of sensemaking for issues such as health care, social and economic justice, and organizational management. Social order is discursively established (Giddens, 1984), and “it is in discourse that power and knowledge are joined together” (Foucault, 1978, p. 100). Therefore, these narrative or dialogic threads reflect and reinscribe power relations in our personal relationships with family and friends, in organizations, and in our communities (Clair, 2006; Mumby, 1987).

The universalizing theories called meta-narratives (narratives that privilege status and promote patriarchy) have often played a crucial role in political, class, and gender struggles (Weedon, 1997). Weedon identified the need for narratives that are non-universalizing, that do not have foundationalist status, and that allow for cultural and historical specificity. As Lupton (2003) asserted, “language does not exist in a social vacuum but is embedded in social and political settings and used for certain purposes” (p. 20).

When stories shift between the boundaries of the public and private spheres, there is often personal discomfort and tension for the narrators of those stories. For example, in their studies on infertility, Harter, Kirby, Edwards, and McClanahan (2005) and Kirkman (2001) found that the very private issue of infertility did not remain inside the home of the individuals or couples experiencing the difficulty. In fact, those who are childless (either by choice or because of infertility issues) are frequently bombarded with countless questions by friends, family, and even strangers who inquire about their childless state, their intentions to have children, and their (in)ability to have children. When women decide to seek help to combat infertility, they must transform the private into public as they tell and retell their stories to medical personnel and others. Also creating tensions
are the socially constructed and canonical narratives that position “women as mothers and men as virile procreators” (Kirkman, 2001, p. 524).

Narratives, often the sites of contested terrain where discourses collide and compete for dominant meaning, serve as a conscious-raising, powerful, and liberating mechanism that is embraced by feminists as a way to open up dialogue and give voice to those who have been cloaked in silence by oppression, marginalization, or fear (Weedon, 1997; Howry & Wood, 2001). Harter et al. (2006) offered this explanation of narratives’ role in the activities of organizations that do the work of social movements: “The structural properties of narratives become powerful repertoires of protest, strategic resources for social change, and the (re) construction of individual and relational identities” (p. 16).

Often the boundaries of autobiographical, organizational, and public narrative blur as stories are told, for example, in an attempt to evoke social justice or change or in an attempt to bring about safer health practices. These stories may take many forms including photographs, skits and plays, television and radio soap operas, written texts, and the oral sharing of traditions, myths, and legends. Examples of initiatives which rely on boundary-spanning stories to elicit behavioral change include the diffusion of innovations (see Cheney, Block, & Gordon, 1986; McKee, 2000; Rogers, 1995), the use of education-entertainment in health promotions and campaigns (see Singhal & Rogers, 1999; Singhal, Rogers & Mahajan, 1999; Singhal et al., 2006), and to disrupt the scripts of poverty and reorder social inequities (see Auwal & Singhal, 1992; Singhal, Rao, & Pant, 2006; Singhal & Rattine-Flaherty, 2006).
An example of using storytelling to disrupt the scripts of poverty and social inequity is StreetWise, an organization based in Chicago. The organization produces a street journal (also called StreetWise) which resembles a typical city newspaper with feature articles on businessmen and women, restaurant and music reviews, crossword puzzles, a sports page, etc. The difference with this newspaper is that it provides employment opportunities to homeless men and women who sell the paper on street corners in Chicago. In their study of StreetWise, Harter, Edwards, McClanahan, Hopson, & Carson-Stern (2004) argued that the organization provides counterstories or counter-discourses that disrupt the dominant cultures’ way of thinking about poverty and the homeless by “privileging personal lived experiences and narrative reasoning” (p. 122).

The newspaper regularly includes feature stories about their successful vendors. These personal stories, which are collected by the organization and disseminated into a public venue, disrupt the master narratives associated with the homeless by eliciting a consciousness of identification and consubstantiality (Burke, 1954/1984). That is, the paper creates a discursive space that uses narratives and counterstories to tell of the struggles encountered in people’s everyday lives, to provide common causes that promote acting together, and to show that the homeless are people just like you and me (Deardorff, 2004). The autobiographical stories “possess the power to fire people’s imaginations and structure readers’ thinking about and responses to social and political issues” (Schroll, 1999, p. 329).

To illustrate the discourse (or common ground) enacted by the street journal which enables the writers, readers, and advertisers to identify with the homeless, one has to only look at the following counter-narrative employed to describe its street vendors.
StreetWise vendors aren’t so different from you. Like you, they’re striving to improve their job skills to achieve more rewarding positions. Like you, they’re dedicated to providing for their families. Like you, they’re athletes and writers, parents and children, teacher and students. (www.streetwise.org/vendor)

A second example of the blurring of organizational, personal, and public narratives to evoke social change involves the stories of Passion Works, a non-profit collaborative art studio housed within a sheltered workshop for individuals with mental and developmental disabilities. In their case study of Passion Works, Harter, Scott, Novak, Leeman and Morris (2006) illustrate how counter-narratives can be used to disrupt stories of domination and to foster social change. Whereas the metaphor of disability as medical condition serves as an anchor in master narratives of exclusion and separation, counter-narratives challenge the status quo and shake up the hierarchy of power which labels the imperfect an inferior class.

Many of the client artists at Passion Works cannot communicate via speech, but they have been able to tell their autobiographical stories through paintings, drawings, and sculptures. The selling to the public of jewelry, prints, metal passion flowers, and other items taken from the renderings of their art work provides a vehicle from which the client artists can tell the world their story and perform counter-narratives of their disabilities. Lindemann-Nelson (2001) asserted that “optimally successful counterstories must be master narratives, since success consists precisely in the counter-story’s becoming widely circulated and socially shared” (p. 157). These counter-narratives are changing the master narratives associated with disability; they are changing the master narratives of the
Passion Works organization and of the sheltered workshop, and through their boundary spanning nature are evoking social change.

The social narratives associated with the homeless, with people who are developmentally or mentally disabled, or with individuals living in poverty serve to (de)legitimate their cultural norms and practices. If we choose to embrace the use of counterstories and/or alternative narratives—to contest, to challenge, and to disrupt the stories we live and tell—we can begin to reshape the dominant societal scripts of exclusion and disparity that exists.

Along with the obvious strengths and benefits that narrative brings to us as storytelling animals, I would be remiss not to touch upon some of the inherent flaws of the theory. Indeed, questions about the power to persuade, the potential to harm, and the ethicality of narratives must be raised and addressed, and scholars must remain constantly reflexive and cognizant of the risks as well as the benefits this powerful force brings to bear.

Although narratives give their teller(s) the opportunity to share lived experiences with others, and to heal, to educate, or to disrupt and challenge dominant societal scripts, this exchange can be painful and/or debilitating for the narrator who has to relive a tragic or traumatic event. There is always the danger that the disclosure(s) may place the narrator in a precarious position if the information is sensitive, inflammatory or incriminating, if the listener(s) do not believe the story, and/or if the listener(s) choose(s) to exploit the knowledge in some manner.

As scholars, we can privilege one person’s lived experience over another, and we can select specific stories and direct the attention to which of these stories get told and
retold, in what contexts, and by whom. The stories we enter into may be messy, complicated, cluttered, and complex. These stories could embed the dominant scripts deeper into the social landscape instead of evoking alternate stories and discourse that brings about change. Being the keeper of another’s story is sometimes risky business because “the receiver of another’s narratives owes something to the teller by virtue of knowing it” (Charon, 2006, p. 55). Indeed, we have no way of knowing which way the pendulum will swing when we decide to share the stories of others. For example, the mobile health clinic has been successful in its use of stories about the poor and the uninsured to secure funding necessary to operate and to serve that population. However, great care must be taken that these same stories do not result in heaping additional shame and stigmatization onto the heads of this already marginalized population.

Ethicality also enters into play as we decide whose narratives and which narratives we are going to use, where, and when. Issues that must be considered include determining how much detail we are going divulge about the storyteller and how much detail we are going to divulge about others inside the story. We are not just (re)telling the stories of our patients, our friends, or our interview subjects. Their stories do not sit quietly by themselves—they are influenced, co-constructed, disrupted, and altered by the others in their lives. When we (re)tell a story, we are pulling those other people into the story often without their permission and without giving them the opportunity to give their side of the story. We should be, I believe, held to the standards of the Hippocratic Oath—we should strive to do no harm with our narrative (re)telling. I will turn again to these issues when I discuss the rigor of narrative research study in Chapter 3.
Thus far I discussed my narrative theoretical underpinnings, explicated what narratives bring to us, explained the nuances between autobiographical and organizational narratives, and offered examples of how these narratives leave private spheres to blur and interface into public spheres. In the following section I move to the storied nature of health care and explore the narratives of illness, health and healing.

The Storied Nature of Health Care

I told that doctor flat out what it was. He looks me right in my face, says, Mrs. Chapman, you can worry a man sick, now, and John has got to work. You let me do the doctoring here, unless you got a sheepskin somewhere I don’t know about.

All I could think was that old story about a wolf in sheep’s clothing. I said, Sheepskin? And he points to a picture frame propped on his desk, diploma wrote in Latin, from some college in Virginia. I said, No, doctor, I got nothing like that.

I did not hold John’s hands, speckled with coal tattoos, out to the doctor, did not say Read this here, doctor, how easy the dust works in under his skin. I did not say, You come home with us. Read his hankerchiefs, read my pillowsips, grayed with dust, sprayed with coal-black flecks of coughed-up muck. I did not tell him my learning come nights, from the ragged, rocky-chested racket of my daddy’s cough and the only Latin we got to show for it is on his stone.
Across disciplines, scholars and practitioners are turning to narrative theory and practice to examine a number of health-care and health-related issues. For example, some therapists have adopted a distinctively narrative turn in therapy (White & Epston, 1990), scholars have explored narrative constructions of binge drinking in public discourse (Workman, 2005), narrative frames for understanding provider-patient interactions (Beach & Mandelbaum, 2005; O’Hair, Scannell, & Thompson, 2005; Sharf, 2005), the role of storytelling in bereavement processes (Bosticco & Thompson, 2005), narrative constructions of health care issues and policies (Beck, 1997; Carmack, Bates, & Harter, 2008), narrative and mental health in primary care (Launer, 1998), narrative care from the nurses’ station (Morgan-Witte, 2005), form, function and ethics of narrative medicine (Charon, 2001), and the importance of narrative based medicine in clinical practice (Beck, 2001; Beck, 2005; Greenhalgh & Hurwitz, 1999). My discussion of intersections between narrative theory and health practice center around three primary themes: (1) illness as a call for stories; (2) the narrative nature of health care; and, (3) social hierarchies of health care.

**Illness as a Call for Stories**

“The power of stories to communicate the human condition in an accessible, inspirational, and therapeutic way is the biggest strength of narratives”

“No story sits by itself. Sometimes stories meet at corners and sometimes they cover one another completely, like stones beneath a river” (Albom, 2004, p. 10).

Ellingson and Albom offer a beautiful synthesis of how very powerful and empowering narratives can be. Albom’s words remind me that human life remains an intertextual and storied experience. Narratives of illness, for example, open us up not just to hear the story of other’s suffering, but also open us out to tell our own story and to begin the phases of the healing process (Bochner, 2002; Frank, 1995). Meanwhile, our lived experiences build one upon another—one story leads us down one pathway only to take a fork in the road as another story, our own or that of another, alters our course time and time again. Like the river flows over the stones, turning them first one way then the other depending on the current, our stories, our narratives, do not sit quietly by themselves but instead overlap, intersect, and offer divergent directions. Indeed, our powerful, therapeutic, and inspirational narratives are fluid—they constantly shift and evolve much like the stones in the river.

In Wounded Storyteller, Frank (1995) maintained that illness is a call for stories, and ill individuals are wounded storytellers. Because narratives are pivotal resources for sensemaking, they allow us to experience, enact, and express sorrow and pain. From Frank’s perspective, ill individuals often feel “shipwrecked” and are in need of restorying their lifecourse—things cannot continue as they once did. He argued, “Reflexively and sometimes prescriptively, illness narratives invoke change, based on understanding illness as a moment at which change is especially possible” (p. 41). Through telling stories and creating illness narratives, Mattingly and Garro (2000) suggested we are able
to construct the self in order to provide meaning and understanding to the health experience.

In the face of inescapable suffering and trauma, storytelling facilitates emergent social selves, relational identities, and co-cultural understandings (Sharf & Vanderford, 2003). From a theoretical perspective, illness narratives provide a significant means for studying the social construction of illness as a rhetorically bounded, discursively formulated phenomenon. The intersection of narrative and health is gaining ground in the social sciences and the medical community. For example, Harter et al. (2005) suggested that narratives are an especially appropriate means of examining issues of health and healing because they wrestle with complexities that face contemporary health care participants: identity construction, order and disorder, autonomy and community, and fixed and fluid experiences. Additionally, scholars have acknowledged the embodied nature of illness narratives—stories are told in and through the body (e.g., Beck, 2005; Frank, 1995). Beck (2005), for example, explored the storying of Cathy Hainer’s battle with cancer as reported in *USA Today*. Through her analysis, Beck argued, “health narratives are necessarily embodied rhetoric—powerful, persuasive, deeply personal yet inherently social” (p. 79).

Illness narratives are appealing and comprehensible because they make use of familiar elements (characters, people who enact the events, scenes, settings, emotions, plots or dramas, etc.) with which we have learned to shape our perceptions of the world (Sharf & Vanderford, 2003). The telling of the story is as important as the story elements that constitute a narrative—illness narratives challenge the voice of medicine as the primary means of understanding health and disease. In particular, Arnstson and Droge
(1987) identified how the following four functions of health-related storytelling and illness narratives help patients: (1) making sense of health and disease, (2) asserting control in the midst of physical and psychological losses, (3) transforming their identities and social roles as a result of altered health and disease, and (4) making decisions about their health.

Frank (1995) offered up his chaos narrative as the most embodied form of story (smoking, overweight, sick spouse). In the mobile health clinic, for example, the CHP staff “hear” chaos narratives continually and attempt to work on small portions of the chaos at a time. For example, an overweight patient may tell a staff member that she has high blood pressure, a sick husband that she is caring for; she just lost her job, is having migraine headaches, and has a bad cough from smoking. The staff member may tell the patient that she needs to lose weight and stop smoking to help control her high blood pressure, but first she needs to concentrate on getting the stress or chaos in her life under control.

Such storytelling can be valuable for patients and providers alike. Frank (1995) aptly encapsulated the power and importance of storytelling in healing:

Storytelling is for an other just as much as it is for oneself. In the reciprocity that is storytelling, the teller offers herself as guide to the other’s self-formation. The other’s receipt of that guidance not only recognizes but values the teller. The moral genius of storytelling is that each, teller and listener, enters the space of the story for the other. Telling stories in postmodern times, and perhaps in all times, attempts to change one’s own life by affecting the lives of others. Thus all stories have an element of testimony … (pp. 17-18, emphasis in original)
Greenhalgh and Hurwitz (1999) concurred, and suggested that “narratives of illness provide a framework for approaching a patient’s problems holistically while possibly uncovering diagnostic and therapeutic options” (p. 48). However, as Charon (2006) cautioned, “we have to learn how to listen to the multiple registers of the body, the self, and the storyline and how to respond ethically and dutifully to what we hear” (p. 182). In the next section, I explore the recent treatments of health care as narratively organized and performed.

The Narrative Nature of Health Care

Narrative medicine is defined as medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved to action by stories of illness (Charon, 2001/2006). The poem at the beginning of this section by Diane Giliom Fisher presents a traditional biomedical script between a doctor and a patient’s caregiver—the doctor prescribes and the loved one’s docile body listens (see Foucault, 1975/1995). Charon (2006) challenged that model of care:

Along with their growing scientific expertise, doctors need the expertise to listen to their patients, to understand as best they can the ordeals of illness, to honor the meanings of their patients’ narrative of illness, and to be moved by what they behold so that they can act on their patients’ behalf. (p. 3)

Rawlins’ (2005) portrayal of his family’s physician illustrates the heuristic merit of Charon’s position. He recounted his physician father’s lessons about adopting a narrative stance toward practicing medicine as he emphasized the importance of “committing oneself to understanding patients’ health concerns and observable symptoms in and through the context of their own lived stories” (p. 213).
Scholars and practitioners across professions and disciplines are exploring the narrative structure of medical knowledge and care, with some urging us to acknowledge and respond to both the social and communal nature of health and healing. Diagnosing an individual’s ailment and developing a treatment protocol is not always the best or only prescription for healing the body and the soul. Frank (1995) suggested there is a difference between “taking a patient’s history” and “hearing the patient’s story” and appealed for a change in how doctors and patients interact during the history-taking exercise. Charon (2001) became confident that the act of narrative writing about patients gave her access to knowledge, about the patient and herself, that would have otherwise remained out of reach. She also found this knowledge changed the dynamics of the interactions, “I also realized that writing about patients changed my relationships with them. I became more invested in them, more curious, more engaged, and more on their side” (p. 84).

Charon (2001) argued that the field of narrative medicine is developing not merely a tool for physicians’ reflection, but a treatment intervention that may hold substantial power. She further argued (2006) that health care providers could engage in better clinical reasoning with a sophisticated understanding of how stories work, a disciplined and rigorous study of storytelling over time, and by becoming informed by the work of Burke among others. Narrative stories show how communication functions to organize experiences and shape meanings by applying theories to lives and by drawing applications from those lives to enrich theoretical understandings (Goodall, 2004).

Charon’s work parallels that of Hunter (1991), who asserted that “medicine is fundamentally narrative and its daily practice is filled with stories” (p. 5). These
narratives—formed by the patient and the physician—are how doctors learn. “The patient’s story of illness, augmented with the results of the physical examination, is interpreted and shaped into a medically plotted version by the light of the physician’s store of clinical information and then compared not only with standardized, textbook plots of the most probable diseases, but also with plots of comparable cases in the physician’s experience” (p. 45).

Two revolutionary health care providers, Drs. Peter Anderson and Robert Lindbergh, have provided us with new ways of looking at health care including complexity science (allows the doctor to interact with a wide range of people using various sciences, not just the usual physics, biology, and chemistry) and patient-centered interactions facilitated by storytelling. Anderson, a pediatric oncologist and professor at the University of Texas M.D. Anderson Cancer Center, takes a slightly unconventional and different approach to doctoring. During his rounds, he takes time to listen to the stories of his patients and their parents, often urging them to sit down with him at his computer and write summaries to co-construct their stories of illness and health. Anderson then uses these summaries to construct his knowledge of the patients’ lived experiences, to gather medical histories, to build relationships with them, and to incorporate their future plans and goals (be it to attend the prom or go on a cross-country road trip) into his diagnosis and treatment regiments (Harter, 2009). By encouraging patients to explore the conditions of their own lives through written narratives or stories, Anderson is helping to provide a reflexive mechanism that allows for the possibility of “rewriting” their stories of illness and health (Lupton, 1995).
For Lindberg, an internal medicine specialist from Connecticut, the practice of medicine is guided by interactions inside the human body and outside in the environments where people live. Lindberg posits that “communication in health and illness constitutes the most vital of human experiences” (Babrow & Mattson, 2003, p. 39), and, as a result, operates outside the paradigm of traditional biomedical scripts by dialoging with patients in hopes of discovering underlying issues that impact their health care. “I let them tell their stories. And, I listen empathically. There are therapeutic effects of telling. People, in part, heal themselves by telling” (in Singhal, 2006, p. 3). Indeed, traditional medical histories and records reflect only a biomedical assessment of the patient; little is written about how patients feel about their diagnosis, how they are coping, or what their illness means to them and their family members (Lupton, 1995). Lindberg argues that better health and faster recoveries are not just enacted through prescriptions or the course of treatment; instead, the healing process is a social phenomenon facilitated through social interaction and relationship building. Lupton (1995) maintained that “apart from their biomedical manifestations, health, illness, and disease may be considered products of cultural practices” (p. 57).

A narrative perspective on healing and the organizing of health care relationships ought to address social, political, and economic forces that (re)produce relations of power within institutions of health care. Lupton (1995/1997) reminded us that discourses of health and illness serve us as the routes through which we understand, think and talk about, and live our bodies, perhaps more than any other system or institution. For example, personal, professional, societal, and bureaucratic factors influence physicians in their choice of naming an illness and how they present this naming to the patient (Wood,
Wood further argued that the “effect of the illness name on the individual patient may be determined not only by individual experience and knowledge but also by social, cultural, and economic factors” (p. 534). In the next section, I focus attention on how discourses, including narratives, organize and structure the world in ways that benefit some individuals more than others.

Social Hierarchy of Health Care

Health care and the medical arena are fraught with power relationships, for example, between patients and physicians, between physicians and nursing staff, and even between the health-care facility and medical personnel. The medical world is also fraught with power relations as they intersect with gender and class. A case in point: Lupton (1995) argued that public health and health promotional discourses shape embodiment and a range of subject positions and, as a result, are coercive, repressive or confining. She further argued, “these bodily practices and sources of subjectivity are not available to all individuals equally, and do frequently serve to perpetuate relations of social inequality, often organized around the drawing of distinctions between gender, categories of sexual preference, ethnicity and social class” (p. 156). Lupton drew many of her insights from Foucault (1972), who believed that space is fundamental in any exercise of power. In his study of space and power, he focused his attention on institutions such as the clinic, the prison, the hospital, and the asylum as he believed these were the sites within which various forms of knowledge and power were inscribed on bodies and souls. He further believed that there is no possible social field outside or beyond power, and no possible form of interpersonal interaction which is not at the same time a power relation.
Feminists and scholars alike have discussed how the medical system might become less hierarchical and more egalitarian in its values and communication styles as the number of women physicians continues to grow (for example, see Charon, 2006; Ellingson, 2005; Johnson, 2006; Lorber, 1997; Turner, 1995). Despite equal numbers of women and men and increasing percentages of people of color being admitted to medical schools, the power has not shifted. Positions in the highest levels of medicine are still largely held by white men and even though women are physicians, the role of a physician remains vested with masculine power (Ellingson, 2005).

Patients get caught up in the hierarchy of power in that health care providers have something they want, for example, an expert medical opinion or diagnosis. The traditional doctor/patient relationship puts the physician in authority while the patient is passive—“a power dynamic that is exacerbated further when the physician holds more social status because of gender, class, race/ethnic, or age difference” (Ellingson, 2005, p. 132).

Women and children living in poverty are horrifically impacted by the social hierarchy and status associated with health care. Ford and Yep (2003) found that women living in poverty are in poorer health than affluent individuals. Critical factors in contributing to the poor health of these women are limited access and availability of health care and the under utilization of existing health care services. In addition, women and children have traditionally been confronted with unique health care dilemmas when seeking medical care including the medicalization of the reproductive processes, over prescription of drugs, and unnecessary surgeries (Nussbaum, Ragan & Whaley, 2003).
In light of these critiques, a number of communication scholars believe it is time to move away from individual level theories of preventative health behaviors to more multi-level, cultural, and contextual interventions (McKinlay & Marceau, 1999; Salmon & Kroger, 1992). Even so, the political rhetoric that calls for social understandings of health care may or may not provide relief for this marginalized group. “To locate ill-health as a social rather than an individual responsibility does not remove blame or moral judgment, it simply shifts blame from stigmatized individuals to the marginalized groups of which they are a member,” argued Lupton (1995), “while at the same time serving to obscure the suffering of individuals, who become anonymous ‘risks’ or ‘threats’ to the commonwealth” (p. 105).

In adopting a narrative perspective, I seek to acknowledge that providers and patients do not communicate in a vacuum. Instead, these storied encounters occur within sociocultural and material contexts that are both medium and outcome of discourses (Sharf, 1993). Institutional patterns establish the conceptual limits for storytelling. As such, narrative scholars should explore how storied performances reflect political and social undertones.

Summary and Research Questions

“What distinguishes narrative knowledge from universal or scientific knowledge is its ability to capture the singular, irre replicable, or incommensurable” (Charon, 2006, p. 45).

As I argued in Chapter One, poverty and social exclusion in a society have a major impact on the health of its population. Both of these factors play a significant role in limiting the availability of convenient and affordable mainstream health care for
women and children living in Appalachia. Drawing on feminist and narrative sensibilities, this dissertation provides an ethnographic account of how the OUCOM mobile and free health clinics address the poverty and health-related issues of this marginalized and stigmatized group. Through the services provided by the clinics, women are empowered to share, and rewrite, their stories of health and illness and they are empowered to take action for themselves and their children by seeking and receiving the health care they might otherwise not be able to obtain.

By situating my narrative orientation amidst a growing body of inter-disciplinary literature focused on narratives, health and healing, I extended the communication discipline’s theoretical and practical reach to include alternative forms (outside the traditional, mainstream biomedical models) of organizing health care resources. Communication scholars and health care providers are beginning to recognize that the organization and provision of health care would be impossible were it not for our human capacity to embody lived experience in narrative form. With its attention to the importance of context and its ability to explore identity construction and to organize our relational and communal lives, narrative theory provided a robust lens through which to expand our discipline’s traditional understandings of health care and health care settings.

Narratives can serve as a conscious-raising, powerful, and liberating mechanism that is embraced by feminists as a way to open up dialogue and give voice to those who have been cloaked in silence by oppression, marginalization, or fear (see Howry & Wood, 2001; Weedon, 1997). In adopting a narrative perspective, I sought to acknowledge that providers and patients do not communicate in a vacuum. As Charon (2006) suggested:
Medicine is itself a more narratively inflected enterprise than it realizes. Its practice is suffused with attention to life’s temporal horizons, with the commitment to describe the singular, with the urge to uncover plot …and with an awareness of the intersubjective and ethical nature of healing. (p. 39)

From a theoretical perspective then, illness narratives challenge the voice of medicine as the primary means of understanding health and disease and provide a significant means for studying the social construction of illness as a rhetorically bounded, discursively formulated phenomenon. Based on the various literatures I reviewed, and inspired by an overarching feminist and narrative philosophy, this project was guided by the following research questions:

RQ1: How (if at all) does narrative activity foster healing and empowerment?

RQ2: How is the storied nature of health care shaped by the mobile nature of the clinic?

RQ3: What symbolic and extra-symbolic forces coalesce in ways that allow women and children living in poverty to be resilient in the face of inhospitable conditions?

RQ4: What counter-narratives (if any) does the mobile health clinic offer to disrupt and challenge traditional biomedical and dominant scripts?

RQ4a: How (if at all) do these counter-narratives impact the health-care experience for this population?

RQ4b: If present, whose interests are served by the counter-narratives?
CHAPTER 3: METHODOLOGY

“A lived experience does not confront me as something perceived or represented; it is not given to me, but the reality of lived experience is there-for-me because I have a reflexive awareness of it, because I possess it immediately as belonging to me in some sense. Only in thought does it become objective” (Dilthey, 1985, p. 223).

Recognizing that lived experience is understood as always already interpreted, there are multiple ways of (re)telling, understanding, and (re)interpreting stories and how they intersect and are interwoven into the social and personal fabric of those with whom we act and interact. As I moved between and co-constructed the stories performed and told by participants (both patients and caregivers), I had to remain reflexive about, and sensitive to, the sometimes treasured, sometimes painful, and sometimes stigmatizing artifacts that I encountered.

Narrative-interpretive researchers rely on a number of methodological tools and practices to collect and analyze data. In some instances, several methods and practices are used either simultaneously or in different stages of the research process. Drawing upon interpretive methods in this dissertation, I adopted feminist and narrative sensibilities and engaged in ethnographic, qualitative research to gain a deeper understanding of the rhythms, rituals and routines of the OUCOM mobile health clinic and the population they serve. Naples (2003) suggested that using a “repertoire of research strategies…would better position researchers to generate knowledge that can support collective action for social, political, and economic justice” (p. 202). Denzin and Lincoln (2000), too, argued that it is important for postmodern qualitative researchers to seek various and alternative
methods for evaluating their work including “verisimilitude, emotionality, personal responsibility, an ethic of caring, political praxis, multivoiced texts, and dialogue with subjects” (p. 10). Being mindful of the suggestions offered by Naples and Denzin and Lincoln, I approached this research from an explicitly broad perspective by casting a wide net that incorporates autobiographical and personal stories, interpersonal interactions, performed scripts, social commentary, and institutional plots that surround an issue or idea over time.

Qualitative research has been broadly defined as a set of interpretive activities which involves a variety of empirical materials including accounts of personal experience; life stories; interview discourse; artifacts; and cultural, historical, and visual texts that describe routine and problematic moments and meanings in lives of individuals (Denzin & Lincoln, 2000). Each practice of qualitative analysis and writing allows researchers to see the world in different ways and in different contexts. As an interpretive scholar, my basic role involved “translating the interests and concerns of one people into the interests and concerns of another” (Denzin & Lincoln, 2000, p 24). Although my interpretive reading of the services provided by the Community Health Programs might not be the best or the only reading of the symbolic and material nature of health care, I optimistically believe that my inquiry will spark or stimulate other alternative readings.

As Alvesson and Skoldberg (2000) argued:

Authorship is about increasing the opportunities for different readings. The reader becomes significant, not as a consumer of correct results—the right intended meaning from the text and its author(ity)—but in a more active and less
predictable positioning, in which interesting readings may be divorced from the possible intentions of the author. (p. 171)

In order to see alternative world views of the mobile health and free clinics and those who participate in the stories of health and healing, I adopted an epistemological and methodological position that allowed me to observe and participate in their lives. These broadly conceived beliefs formed the framework for my research questions and my research design.

In this chapter, I describe and outline the components of my research design. I begin with an orientation to my understanding of, and approach to, fieldwork inspired by ethnographic sensibilities. Next, I describe the research settings and will identify the various participants with whom interaction occurred. Third, I explain my methods of data collection including participant observation, interviews, and analysis of organizational documents. Finally, I conclude with a discussion of how the collected discourses were analyzed.

Fieldwork Inspired by Ethnographic Perspectives

Ethnographic field research, also called participant observation or fieldwork, involves the study of groups and people as they go about their everyday lives (Emerson, Fretz, & Shaw, 1995). An immersion into the context of social interaction (Clarke, 2005), ethnographic fieldwork involves careful observation that is documented in extensive fieldnotes (Lindlof & Taylor, 2002). Ethnographic fieldwork is a “representation of a culture that carries quite serious intellectual and moral responsibilities, for the images of other inscribed in writing are most assuredly not neutral” (Van Maannen, 1988, p. 1).
Narrative methodology invites alternative considerations of narrative form, structure, function, and content. As such, narrative ethnographers seek to reclaim the personal experience of everyday life for communication research in ways that challenge existing ways of thinking, writing, and speaking about those issues. Narrative stories show how communication functions to organize experiences and shape meanings by applying theories to lives and by drawing applications from those lives to enrich theoretical understandings. Narrative ethnography is holistic—it is about the interplays of “work in our lives and our lives at work” (Goodall, 2004, p. 188).

The narrative ethnography processes of collecting data, making sense of them, and writing about them do not occur in a linear fashion; they are interwoven. Ellingson (2005) suggested that “Writing narrative ethnography is a process of constructing narratives from fieldnotes, memories, and other written accounts. Narratives are constructed to make sense out of what is experienced” (p. 156).

The objective of ethnography is to produce thick descriptions of the multiplicity of conceptual structures of cultural life (Geertz, 1973). The practice of ethnography is described as experiencing, enquiring, and examining (Wolcott, 1999), and is “about experiencing and remembering; ordering and giving frameworks to our memories” (Coffey, 1999, p. 127). Ethnographers turn the experiential style and the participating-to-write style into written texts in different ways. Some maximize their immersion in local activities and their experience of others’ lives, deliberately suspending concern with the task of producing written records of the events. Researchers using this method focus efforts on figuring out—holistically and intuitively—what people are up to.
Ethnographers wait until some later point to turn to the task of narrating events for external stakeholders like academic disciplines.

Czarniawska (1998) argued that one reason for researchers to go to the field is “because it is there that narratives abound” (p. 20). Immersion enables ethnographers to directly experience the ordinary routines and conditions under which people conduct their lives as well as the constraints and pressures under which they live (Emerson, Fretz & Shaw, 1995). Goffman (1989), too, argued that immersion was a key element in directly experiencing lived narratives and called for researchers to:

subject yourself, your own body and your own personality, and your own social situation, to the set of contingencies that play upon a set of individuals, so that you can physically and ecologically penetrate their circle of response to their social situation, or their work situation, or their ethnic situation. (p. 125)

Feminist ethnography, which is almost always done by women, seeks out and writes about experiences of women within and between cultures (Jones, 1998). According to Howry and Wood (2001), feminism serves four functions: (1) it names women’s experiences into existence; (2) it provides a premise for understanding and articulating women’s experiences; (3) it provides a means of healing; and, (4) it enables feminist activism. As a feminist interpretive scholar, one of my goals was to open up or create a discursive space where invisible women (and their children) could narrate how they shape meanings and experience health and healing.

My own narrative standpoints, which include the pain of poverty and stigma, served as a double-edged sword throughout my journey. In order to navigate the murky waters between researcher and interpretive possessor of the stories, I needed to look
outwardly to see the “social action from the actors’ point of view to understand what was happening” (Lindlof & Taylor, 2002). My personal and deep-rooted connection to this population had the potential of allowing me to form a spirit of identification and consubstantiality as an insider within. However, that same insider status meant that I had to also be ever diligent to use a reflexive lens for viewing collected discourses. Although my account of the storying of health care in a mobile clinic is no doubt shaped by my standpoint and my lived experiences, I believe my account is fair and accurate and not overly partisan. While acknowledging and celebrating my positionality and “interrogating the relationship between my standpoints and the implicit and explicit claims I made” (Ellingson, 2005, p. 151), I had to become “answerable for what I learned how to see” (Haraway, 1988, p. 583). Coffey (1999) beautifully synthesized the tensions inherent in this process:

Connecting and writing lives is also about connecting and writing about the embodiedness and physicality of the self. The peopling of biography and ethnography is physical as well as social and cultural. In writing ethnography, we are engaged in a practice of writing and rewriting the body. (p. 131)

In my study of the mobile and free health clinics, fieldwork offered a number of benefits over experimental, quantitative, or highly structured qualitative data collection methods. Furthermore, fieldwork allowed me to look holistically at content, process, language, and behavior in a medical context, rather than simply identifying or counting types of communicative practices of patients, physicians, or other health care providers from taped interactions or transcripts. As a participant observer, I was able to observe interactions not only among the patients and a variety of health care providers, but also
among the patients and their companions and among the health care providers themselves.

Settings and Participants

As I discussed in Chapter 1, my involvement on a research team four years ago introduced me to the Ohio University College of Osteopathic Medicine’s Community Health Program (CHP). Since that time, I have been involved with the activities of the clinic as a volunteer, patient, and researcher. The primary mission of the CHP’s mobile health and free medical clinics is to provide health care to traditionally underserved populations—particularly Appalachian women—who either cannot afford medical care or who have difficulties physically accessing medical care for themselves and their children. The free or reduced services provided includes breast and cervical cancer screenings for those who live at or below 200% of the poverty level, free medical clinic services to the uninsured who live at or below 150% of the poverty level, healthy adult screenings (glucose, blood pressure, and cholesterol), and an adult and child immunization program.

Formed in 1996 and serving 21 Ohio counties (11 of which are considered Appalachian), the Community Health Programs grew out of a Childhood Immunization Program (CHIP). Originally working out of one 40-foot van, the CHP staff quickly realized there were too many individuals needing health care services for one van to handle. As a result, a second mobile unit was added in 2001. The Healthy Adult Project (HAP), which provides blood pressure, glucose, cholesterol, breast, and cervical screenings, was also added as a free service. The CHP has continually grown, and in
addition to the services mentioned above, they also offer car seat and well child/well family programs, prenatal and baby steps services, and tuberculosis prevention.

The first free medical clinic was set up in a former elementary school building in a small rural community in Athens County two years ago in the hope of transporting medical care to a difficult-to-reach population. Again, CHP staff soon realized that one free clinic was only scratching the surface of need in the southeastern Ohio region. As a result, a second free clinic was added inside the City of Athens last year. While the CHP now offers a free medical clinic, immunizations, and breast and cervical cancer screenings at two fixed locations on a limited basis, most of the health clinics are still conducted in the two mobile units which are set up at various locations including parking lots, driveways, local school buildings, senior citizens centers, and grocery stores. Last year the mobile unit traveled 12,900 miles to provide free medical services to uninsured patients.

The primary CHP staff consists of one director, one administrative assistant, one full-time and two part-time van drivers, one nurse practitioner, one certified medical assistant, six registered nurses, and one or two occasional rotating physicians (primarily at the monthly free clinic). Often osteopathic medical students or students in the AmeriCorps program will observe and assist the nurse practitioner during the clinics. The long-time nurse practitioner recently moved out of state and a new staff member was hired to replace her. In addition, one of the long-term nursing staff retired and a second relocated. I was anxious to explore the dynamics between and among the new and veteran personnel.
To gain access to the mobile and free clinics for the purpose of this project, I met with the director of the CHP to determine the extent of access she would feel comfortable granting. She was familiar with my previous work and granted access to all of the programs under the CHP umbrella as she believes my research project is important and the results invaluable to CHP as a whole (see permission letter in Appendix A). Included in this permission was the clearance to ride with the mobile van as frequently as I wished and to observe the medical interactions in the free clinics and the prenatal services program. The one caveat required was that I ask for and receive verbal permission from both the staff member and the patient before entering the treatment room. To remain in compliance with IRB standards, I had all patients complete an approved IRB consent form before interviewing or observing their medical interactions. The director granted permission for me to collect data through in-depth interviews, participant observations, and document collection and analysis. In return, I promised to assist staff with marketing ideas and grant-writing endeavors, and to offer a synopsis of my findings at a future CHP staff meeting.

The participants in this study included the medical staff of the mobile and free health clinics, the staff of the prenatal services program, and the patients for whom they care. These observations included caregiver/patient interactions, medical staff interactions with one another, and patient and staff interactions with patient companions. I also conducted several in-depth interviews with patients, administrative stakeholders, and medical staff (see Appendix F and G). While in the field, I remained open to participating in a variety of related activities such as staff meetings and community health fairs.
Discourse Collection

Prior to beginning observations and data collection, I submitted a proposal for approval to the Ohio University Institutional Review Board (IRB) (see Appendix B). Once permission to proceed had been granted, I began my observations and data collection. During the collection process, I kept a research log of all activities which included the day of the week, time, location, type of activity, and trace artifacts collected (see Appendix E).

In order to provide a “thick description” (Geertz, 1973) of my observations, settings, themes, and participants, I employed a variety of methods for collecting data. I conducted numerous field observations in the mobile and free clinics and at River Rose OB/GYN where the prenatal program is administered. I also conducted informal interviews with participants after their appointments followed by formal in-depth interviews with selected staff, patients, and relevant stakeholders starting in September 2008. Since I was already familiar with the services provided by the mobile clinic and the prenatal program, I believe this time period provided me with ample time to collect an adequate amount of observational data.

In the following section, I outline each of the three distinct methods of data collection I used in this study, beginning with an overview of participant observation.

Participant Observation

For this study, I adopted what Lindlof and Taylor (2002) called a “participant-as-observer” role (p. 147). The term participant observation implies that the “researcher is a participant in interactions, but also somehow apart from them, able to observe her or himself interacting with others” (Ellingson, 2005, pp. 155-156). While in the field over a
six-month period, participant observation was my primary method of data collection. Through the method of immersion, I was able to learn more about the setting by “looking and listening, watching and asking.” (Lofland & Lofland, 1995, p. 19). The participant observations helped me frame and understand the interworkings and deeper structure of the CHP and its patients while leading to a “familiarity with opaque background knowledge and practices” (Pollner & Emerson, 2001). My role within this setting was that of an “outsider” on the inside. I did not conduct covert observations; my status as a researcher was clearly communicated to all participants (Lofland, Snow, Anderson, & Lofland, 2006). As noted earlier, my negotiation of the researcher role began with my involvement with a previous research team which looked specifically at the mobile health clinic.

To observe the interactions of the mobile clinic, I traveled with the staff and, in addition to shadowing them while they interacted with patients, I assisted with set up and patient intake as needed. The extra contact time traveling with staff and participating in pre- and post-clinic duties gave me an opportunity to form relationships with the staff, to observe their interactions with one another without the distraction of patient need, and to listen to how they narrate health and healing within the context of the CHP.

The amount of time spent per observation depended on the location of the clinic and the nature of the services being conducted. For example, an average breast and cervical screening clinic usually took six to eight hours counting the travel time to and from the site. Observation time in the free clinics varied with location, with rural clinics logging more hours than the local clinics. In the case of the rural clinics, the drive time on the van to and from the area provided additional opportunities to observe and interact.
with the staff. Observation time in the perinatal program ran an average of two to four hours depending on the patient load on a given day. My goal was to participate in at least two or three field observations—mobile, free clinic, or prenatal program—each week.

When the opportunity presented itself, I attended CHP staff meetings to observe the interactions between the director and her staff and between staff members outside the field setting. These observations gave me a glance into the window of the organizational workings and underpinnings of the CHP. I believe the data gathered in this setting informed and guided some of the stories of care experienced in the field.

During the observations, I took handwritten field notes and attempted to document key phrases of conversation verbatim. Fieldnotes are useful in this type of research as they describe places and people and events and they are used as textual space for recording our emotions and personal experiences (Coffey, 1999). Throughout the observations, I tried to reflexively account for how I as a participant observer potentially affected the performances, including what was observed and how it was interpreted.

All my fieldnotes were transcribed into full sentence form as soon as possible after each observation so that I was able to keep impressions, feelings, questions, reactions, and insights fresh in my mind. As suggested by Patton (2002), I used specific language and direct quotations of participants whenever possible. When, how, and where the fieldnotes were written changed depending upon the circumstances (Emerson, Fretz, and Shaw, 1995; Glesne, 1999). For example, I was mindful not to make patients or staff members feel uncomfortable or fear that I was writing something negative or harmful about them by jotting notes when they were sharing sensitive information. I also did not want to give the impression that I was not listening or to get so absorbed in capturing the
written that I missed subtle nuances of the message or missed important and telling nonverbal cues. All notes were typed, dated, and stored on my personal home computer for which only I have a password. The fieldnotes were used during the analysis process to identify themes or areas of interest.

Not only did I spend time as a participant observer, I also spent time as an observer as participant (Ellingson, 2005; Lindlof and Taylor, 2002). This method consists of interacting continually with research participants as I observed them interacting with others. For example, I assisted with patient registration, helped hold and entertain children getting immunizations, loaded and unloaded supplies, ate lunch with staff members and sometimes patients, and assisted with the set up of clinics and health fairs. In order to gain a better understanding of treatment protocol, I sometimes became a clinic patient and underwent various health screening processes (for example, glucose and cholesterol level testing). By becoming part of the day-to-day activities, I had hoped to diminish my presence as strictly a researcher and to gain the trust and respect of both staff and patients. Through the sharing of myself and in letting participants know about me over time, I believe I developed a reciprocal relationship in which to learn about their worlds, to invite them to glimpse mine, and to enter theirs to some degree (Ellingson, 2005). Just as the CHP mobile unit transports medical care, education and intervention to their patients, the data I gathered will be used for “transportation into a narrative world” (Green & Brock, 2000; 2002) as I seek to co-narrate the experiences of my research participants. Charon (2006) spoke to the importance that competent narrative skills offer to researchers:
Becoming competent in narrative skills opens up practice. It does not simply shift some habits or routines. It changes what we do with patients, with colleagues, with students, and with the self. Its implications reach to the health care professional-patient relationship, health professions training, programs for professionalism and humanism in health care, and the practice of narrative bioethics, as well as the structural aspects of routine medical practice, the economics of care, the means to support health care equitably, and the imperative to improve the safety and effectiveness of the American health care system. (p. x)

Appendix E provides a copy of the research log I used to keep track of ongoing research activities. In total, I spent 224 hours in the field over a six-month period and authored 313 pages of double-spaced field notes.

Interviews

Both informal and in-depth interviews were conducted with patients from the various CHP clinics, with the staff members of each venue, and with appropriate administrative stakeholders (for example, the CHP director). Researchers argue that interviews are effective in gathering stories and in retrospective accounts of experience because they help facilitate and create interactions between the researcher and his/her participants (Fontana & Frey, 2000; Holstein & Gubrium, 2002; Rubin & Rubin, 2003). Interviewing also provides a way of “generating empirical data about the social world by asking people to talk about their lives” (Holstein & Gubrium, 2003, p. 3). After all, who knows about their lived experiences better than the participants themselves—they are the experts and the authorities of their own life stories.
Interviews are seen as “accurate pictures of respondent’s lives and selves” (Fontana & Frey, 2000, p. 646) as they provide a data gathering space for allowing people to tell the stories of their lived experiences in their own words, at their own pace. A comfortable interview space and atmosphere (chosen by the interviewee if possible) will provide opportunities for stories to emerge outside a sometimes cold and sterile clinical or medical environment. Because of their interpersonal nature, interviews can also provide the researcher with a mechanism for immediate clarification that other forms of data collection, such as surveys and document analysis, cannot offer.

During the one-on-one interviews I conducted, I used predesigned, yet semi-structured interview protocols for (a) patients, (b) staff, and (c) administrative stakeholders to guide the process. Although questions were developed in advance of the interviews, an emergent, free-flowing approach was adopted in order to create a flexible space for participants to talk about their lived and unique experiences in a comparatively unrestricted manner (see Appendices F and G). Interview questions were revised or reworded to continually strive for thicker descriptions as different issues emerged and bubbled to the top during field observations and during the interviews.

Over the course of my observations, I conducted a total of 84 interviews, 15 with staff and 69 with patients. The interviews lasted anywhere from 10-90 minutes. In terms of patient interviews, I conducted 61 shorter and informal interviews with patients after their appointments or clinic visits. The interviews with these patients were conducted in spaces where staff members were not present nor could they hear the interactions. In consultation with members of my dissertation committee, I decided that informal interviewing techniques were most appropriate with a population of individuals who might not feel comfortable
inviting a researcher into their homes or have the resources to travel to off-site locations. The shorter, informal interviews were convenient both in terms of space and time—I spoke to individuals after they had had a recent encounter with mobile clinic staff members. The longer and in-depth interviews were conducted with staff (15) and patients (8) at a variety of off-site locations. The 8 patients with whom I conducted in-depth interviews were selected because of their willingness to invite me into their homes or their ability to meet with me at an off-site location. I also conducted the interviews with patients who had used different types of clinics or services so that I could get a better overall sense of their impressions. As a result, two patients were from the well child clinic, two patients were from the perinatal program, two patients were from the breast and cervical cancer screenings, and two had used the free clinics. All in-depth interviews were digitally recorded and then transcribed, resulting in 396 double-spaced pages of transcription. Other data gathered from patients while they were waiting for their appointments, etc., was incorporated into my field notes (see Table 1 for a breakdown of patient marital status). The transcripts were used to solidify ideas and impressions, to look for emergent themes, and for member-checking purposes. The transcripts were stored in a locked file cabinet in my home office.

Document Analysis

Organizational documents are critical to the functioning of the organization as they not only provide an enduring historical context and insight, but a road map into the future of the organization as well. Like interviews and participant observations, the analysis of these documents helps researchers gain a deeper understanding of the organization’s structure. For example, these documents can help recreate past events that the researcher was unable to observe, and they can provide a glimpse into the organizational culture, how the culture is maintained, and the resulting impact upon the
people who come up against that culture. Lindlof and Taylor (2002) argued that document analysis can be linked to and confirm, “the talk and social action contexts that the researcher is studying” (p. 117).

As I carried out my research with the CHP, I examined a number of documents including newspaper and newsletter articles, memos, medical procedure pamphlets and informational sheets, clinic advertisements, mission and goals statements and the organization’s web site. As I examined the artifacts, I compared the information emerging from the public discourse and patient stories with that of the organizational documents.

Another reason that I examined the organizational documents was to ascertain the readability and relevance of documents for the population being served. If the patients cannot read or understand the documents, for example, then the material is of little use. In addition, the CHP director and certified medical assistant asked me to help with crafting more effective informational flyers to advertise upcoming clinics and to help identify more prominent, high traffic locations for their display. The CHP staff did adopt some of the changes I recommended (for example, including tear-off tags for clinic phone numbers on flyers) and I believe my input helped to build goodwill and a stronger relationship with CHP staff. I also believe these changes positively impacted or facilitated patients’ acquisition of medical care.

In this section, I first discussed the use of ethnographic fieldwork in interpretive research and how ethnography helps to reclaim the personal experience of everyday life for communication research in ways that challenge existing ways of thinking, writing, and speaking about those issues. Second, I outlined the setting and participants of my
study. And, third, I discussed my methods of discourse collection which included participant observation, interviews, and document analysis. Now I turn to a discussion of the data analysis procedures and how I engaged with these procedures to make sense out of the various types of data.

Data Analysis

Generally, I relied on the constant comparative method, one aspect of grounded theory developed by Glaser and Strauss (1967), to conduct a thematic analysis of the discourses collected. One of the most influential and widely used modes of carrying out qualitative research, these procedures are being used by practitioners in fields such as education, communication studies, nursing, public health, and social work (Strauss & Corbin, 1997). Examples of health care work that have been conducted using grounded theory include the study of chronic pain (Baszanger, 1997); identity dilemmas of chronically ill men (Charmaz, 1997); temporality and identity loss due to Alzheimer’s disease (Orona, 1997); and medical technology in the intensive care nursery (Wiener, Strauss, Fagerhaugh, & Suczek, 1997).

The constant comparative method begins with data reduction and interpretation and is concerned with generating and plausibly suggesting many categories, properties, and hypotheses about general problems. According to Charmaz and Mitchell (2001), to make connections between and among events throughout the research process researchers must compare emergent data with the earlier data from the very beginning of the research; compare data with emerging categories; and demonstrate relations between concepts and categories. Boje (2001), too, proposed that the purpose of constant comparison is to do the “data collection, coding and analysis as you go” (p. 51) instead of
waiting until the end to code and analyze for results. The strategy of comparative analysis for generating theory, according to Glaser and Strauss (1967), “puts a high emphasis on theory as process; that is, theory as an ever-developing entity, not as a perfected product” (p. 32). This approach presents a practical, step-by-step method for carrying out research (Rubin & Rubin, 2003).

To embrace the constant comparative method, my analysis began as soon as I immersed myself into the observations of the CHP clinics and as I conducted interviews with patients and caregivers. I then read all transcripts and documents to develop a sense of the data as a whole. Then, through an ongoing process of reading, rereading, and coding, I sought out both patterned regularities in the way participants’ accounted for their lived experiences of health and healing as well as counter-evidence and alternative viewpoints. The data was then analyzed inductively to gain a holistic sense of the discourses and to identify emergent themes, patterns, and meanings in the participants’ accounts and performances until saturation occurred. As will be discussed in more detail below, the data was also useful for member checking purposes.

Member Checking

The constant comparative method uses member-checking processes to ensure the viability of the knowledge claims developed. Member checking entails “taking findings back to the field and determining whether the participants recognize them as true and accurate” (Lindlof & Taylor, 2002, p. 242), thereby soliciting the informants’ “views of the credibility of findings” (Glaser & Strauss, 1967, pp. 98-99). I did not envision member checks as ensuring that I captured the “reality;” instead, I hoped they would
offer participants the opportunity to reflect on the plausibility of interpretation I crafted based on the experience I observed and they shared with me.

The in-depth interviews not only gathered additional information about the area of research, they also provided an opportunity for member checking to make sure that concepts, procedures, or impressions were understood correctly. By member checking, I do not mean to imply that running my observations by research participants proved that I was right; rather, this feedback assisted me in telling the stories of my research participants to the best of my ability. By asking questions such as “What did I get wrong?” or “What else should I know?”, member checks serve as possible corrections or modifiers to researcher interpretation. A benefit of member checking is that an impetus is provided to engage in new or continued dialogue with the participants. In turn, this additional or corrected information can help the researcher continue to analyze an event or discover something that might have been missed previously. The member checking allowed staff members to add details that I had not captured or had not correctly transcribed. In a couple of instances, staff members asked that I delete responses they felt uncomfortable with leaving in writing. As I analyzed my data and completed member checks, I embraced the standards of rigor discussed in the final section of Chapter 3.

Standards of Rigor

Standards of rigor cannot be abandoned when conducting interpretive research. Even though we recognize that knowledge is situated, temporary, partial, and indeterminate, interpretive researchers must still demonstrate the reasonableness of their claim(s).
To assess the standards of rigor, it is first important to understand the issues and challenges associated with conducting qualitative research. Power relations between researchers and participants, for example, cannot help but shape and influence the “data” that are collected. Ellingson (2005) recognized that it is impossible for anyone, no matter how reflexive, to completely escape her or his standpoint when conducting research (and I would add that it is difficult to put aside your personal biases as well). Still, she argued that for narrative-interpretive research to pass the test of rigor, an “acknowledgement of the ways in which power operates to promote certain perspectives and silence others is vital to the construction of an ethnography” (p. 137).

Another element of strong qualitative research is that of reflexivity. Frank (1995) suggested that reflexivity is a vital step in assessing the rigor of a narrative research project and argued: “The first lesson of thinking with stories is not to move on once the story has been heard, but to continue to live in the story, becoming in it, reflecting on who one is becoming, and gradually modifying the story” (p. 159). Lincoln and Guba (2000) also argued that reflexivity “forces us to come to terms not only with our choice of research problem and with those whom we engage the research process but with ourselves and with the multiple identities that represent the fluid self in the research setting” (p. 183).

Interpretive research is, by its very nature, a messy undertaking. Clarke (2005) recognized this messiness and suggested that:

We need to address head-on the inconsistencies, irregularities, and downright messiness of the empirical world—not scrub it clean and dress it up…This does
not mean presenting raw data—but rather doing even more analysis and extended reflection that can take rawness into fuller and more explicit account. (p. 15)

The messiness of this research impacts not only those within our research scope, but reaches outside the world of our participants to entangle and complicate other people’s lives. For example, when telling the stories of our participants, we frequently pull others associated with them into the story, often without their permission and without giving them the opportunity to give their side of the story. And even when we can drill down and focus on (re)telling the stories of only our participants, how much of the detail that has been entrusted to us should we share or have the right, morally and ethically, to share.

Through the sensemaking and analysis of my data, I will seek to offer a messy and multi-vocal portrait that offers nuanced understandings including disconfirming evidence.

Bochner (2002) identified four specific questions that he believed narrative inquiry poses and that all researchers should confront in their attempt at meeting the standards of rigor and the associated potential to create messiness. These questions are: (1) “What kind of relationship should exist between the researcher and the research participants?; (2) How should the experience and/or voices of the participants be represented in the research story?; (3) Whose interests are served by the presentation and/or performance of the research?; and, (4) What are the researcher’s ethical obligations to the participants?” (p. 92).

Member checking is a good way of determining how the participants feel about what you have written. At this member checking stage, feedback from participants can help researchers in their attempt to offer well-reasoned stories, they can indicate who they
feel must be removed from the stories, and they can indicate their comfort level with what is being told.

Frank (2005) aptly summarized the position of the interpretive researcher’s final test of rigor when he argued:

The research report must always understand itself not as a final statement of who the research participants are, but as one move in a continuing dialogue through which those participants will continue to form themselves, as they continue to become who they may yet be. …. Narrative analysis can never claim any last word. (pp. 966-967)

As I moved forward to the fieldwork and then to the analysis portion of this dissertation, my goal was not to put forward an all-encompassing, final, only, or best account of this research context. My goal was, instead, to negotiate and open up a discursive space that allows the participants (patients, staff, stakeholders) of this study to tell their stories of health and healing. My intention is to provide a vehicle through which those stories can disrupt and challenge the traditional biomedical models of health care and spark additional dialogue that leads to more questions and eventual change.
CHAPTER 4: STORYING HEALTH IN THE MIDST OF POVERTY

Memories are often triggered at the least expected moments from seemingly unrelated circumstances. Such was the situation I found myself in during a meeting between the CHP perinatal coordinator and the office and nursing staff at a local doctor’s office. During her presentation to the staff, Molly explained how the perinatal program worked, who qualified for referral, and how the staff should handle the referrals. Molly also explained that many of the women who would talk with her in the doctor’s office would not participate if she tried to approach them in their homes. Two of the major factors contributing to this circumstance, Molly further explained, is their fear of having their children taken away and/or because they are ashamed of their living conditions. One of the nursing staff spoke up and said she didn’t understand why the women would be worried about their housekeeping skills or the condition of their homes when a visit from social services or the CHP could provide assistance in the care of their children. Another nurse, Kathleen, spoke up and said “I think some of them are embarrassed by the way they live; by the condition of their houses. Some of them are ashamed at the way they have to live.” Molly shook her head yes in agreement and remarked that Kathleen was absolutely right—embarrassment and shame play a major role in women rejecting help via the home visit approach.

I shook my head yes at Kathleen’s observation too, as I remembered how ashamed I was about the condition of my house growing up. The conversation took me back to a memory of when I was in seventh grade and the school bus broke down in front of my house. Since it was winter and freezing cold, the bus driver asked my mom if the riders could come into our house to stay warm while they waited on another bus. The
situation put me into a state of duel panic. Would I be embarrassed because my mom, who was an extremely closed and private person, refused to take the children inside? Or, would I be more embarrassed to have them see the conditions in which I lived? Somewhat to my surprise, mom agreed to let the 8-10 children into our house to await the new bus. As we all huddled in the living room around the lone pot-bellied coal stove that heated our whole house, I was extremely anxious for the bus to come and get those kids out of my house before something bad happened. My biggest fear at this point was the inevitable need of someone having to use the bathroom because we did not have indoor plumbing—we only had an outhouse (later in life I learned that we were rich by comparison as we had a two-seater outhouse). Luckily my angst was for nothing as no one asked to go to the bathroom that morning. Later on that week one of the riders, Judy Howland, told me that she was surprised how clean my house was on the inside considering how horrible it looked on the outside. When I looked at my house, I didn’t see the clean inside. I was focused on what others who were passing by saw—a shack with ripped and often missing black tar paper that partially covered the exposed wooden frame.

Substandard housing is only one of many issues faced by the women with whom I interacted during my observations with the CHP clinics. The majority of these women live on meager sums of money from pensions, survivors’ benefits, unemployment, or low-paying jobs. And, although many of them hold down two or three jobs, they still have difficulty meeting their monthly bills and putting food on the table. Therefore, health insurance, preventative or regular doctor visits, and life-sustaining medications are luxuries these women simply do without.
Individuals who have never experienced this type of poverty first hand often have a difficult time grasping the bleak terrain and the struggles faced in daily survival. For example, an AmeriCorps employee who works with the CHP recalled her first brush with poverty in Athens and nearby counties.

When I moved here and started driving around and exploring, it was like finding the skeleton in the poverty closet of the United States. I had no idea this type of poverty existed. I figured it did somewhere, but I had never seen it face to face and I was horrified and depressed by it and I was really angry about it. (Staff interview)

Gina’s story illustrates one of the difficulties that people living in poverty face—that of being (in)visible to mainstream society. We have all heard about poverty, and not a day goes by that we do not hear media reports of how governmental cuts in subsidies and programming are eroding an already shaky foundation for “them”. On a local level, for instance, Ludwig and Phillips (2009) reported that the worsening Ohio economy has led to substantial funding cuts in state aid to the medical college. These reductions might, in turn, lead to reductions in the amount of free and reduced cost health services the CHP will be able to provide in 2009. Most of us, however, are shielded from many of these day-to-day realities that exist in the poverty closets of Appalachia.

In this chapter, I move between the stories shared by the patients and the staff members of the CHP during interviews or from notes collected during observations in the field. I collected data through in-depth interviews, participant observations, and document analysis during multiple free clinics held at various locations within Athens, Meigs, Jackson, Hocking, Ross, and Vinton counties in Ohio. I developed themes from
multiple and careful readings of the discourses collected. To protect the identities of the individuals, the names of the clinic locations were changed and pseudonyms were used throughout the chapter. For clarity purposes where necessary, CHP staff members have been identified by using a job title (this practice does not pinpoint one specific staff member as more than one person shares the same job title) and I have indicated when a quote or story belongs to a patient. As a member checking measure, each staff member was given a transcribed copy of their interview. They were then given the opportunity to clarify, to include additional information they felt was important, or to omit responses they believed could harm them or their patients in some way.

The stories shared within the three themes are important as they open a crack in the door of the poverty closet allowing the people dwelling within to give voice to their lived experiences of health care in the midst of poverty. The stories also provide the perspectives of the health care givers who must perform a triage around, with, and through their patients’ stories in order to administer medical care using a prioritized approach. My voice will be intertwined within or beside these stories because in many ways, their stories are my stories. My hope is that, by sharing our stories, this chapter will paint a portrait that evokes emotional connection and spurs intellectual debate. This journey for me was a roller coaster ride of emotions—sometimes painful, sometimes cathartic, always humbling, and ultimately fulfilling because of the opportunity it presents to give space to those who have been invisible for far too long.

Although the three thematized narratives discussed below are presented in a linear fashion, they actually do not (and I submit cannot) stand alone—they intersect with one another and often reveal common experiences shared by multiple storytellers, both
patients and care givers. Each of the three key themes is accompanied by sub themes that contain narratives which further explicate the lived experiences of the research participants.

I begin with the theme of “(In)visibility: Finding the Skeleton in the Appalachian Poverty Closet” which embodies both the patients’ and staffs’ endeavors to characterize and understand the role (in)visibility plays in obtaining and/or providing health care for those living in poverty. The second theme, “Barriers to Care: Falling Through the Cracks,” offers narratives depicting how factors such as money, mobility, flexibility, lack of knowledge, fear, stigma and health legacies impact access to health care. The final theme, “Assembly Line Medicine: Changing Parts on a Car,” interconnects with the (in)visibility experienced by patients when receiving health care via providers and institutions which follow a traditional biomedical model of care.

(In)visibility: Finding the Skeleton in the Appalachian Poverty Closet

My dad had a severe heart attack when I was six years old. He worked in the coal mines and I remember him coming home from work that night and how ghostly white his skin was under the black coal soot. I didn’t know why his skin was glowing through the sooty black, but I knew something wasn’t right. When he came home from the hospital, he was confined to bed rest for several months. I remember my mom crying because we didn’t have any money to pay the hospital and doctor bills. And she was worried because the doctor told my dad he would never be well enough to work again. We were already poor, but we were about to get even poorer.

Somehow mom got us signed up for welfare (in later years she would swear that it wasn’t a massive coronary, but the shame of being on welfare that eventually killed my
dad at age 53) and we began to get food stamps. We were also eligible for government food rations, called commodities, and would stand in long lines to receive our share of canned salmon, cheese, butter, and a canned meat product that resembled dog food (no wonder I detest Spam to this day). To make extra money, my mom planted a larger garden and my parents and I would drive into town where they would set up a “farmer’s market” on the street corner and sell the extra produce. As I watched my mom use food stamps at the grocery, I wished with all my heart to be invisible to the others in the store. As I stood in the food line to receive our ration of “commodities,” I longed to be invisible to those driving by the warehouse. And, as I stood on the street corner in downtown Jackson, I prayed that the sidewalk would open up and swallow me before my classmates or their parents would see us. Ironically, being part of the invisible population forced us to engage in very visible activities to survive. The dissonance that comes with being invisible in a visible world, I believe, is firmly and deeply connected to the shame and stigmatization many associate with being poor.

The first theme that bubbled up from the discourse (as perceived through my senses) was that of (in)visibility—being a skeleton in the poverty closet of the United States. This (in)visibility takes root and is reinforced in a variety of ways including socioeconomic status, culture, tradition, pride, and stigmatization.

Not everyone who lives in poverty is unemployed or uneducated. What is common, however, is that those who are able to find employment usually end up working for minimum wage, they work swing shifts with varied days off, and they are seldom scheduled for 40 hours per week (by keeping them under 40 hours per week, businesses are not required to offer benefits). What is also common is that being employed does not
necessarily ease their feelings of (in)visibility. Rita, a breast and cervical screening patient, told me about the part-time job she holds at K-Mart. She smiled when she talked about how hard she worked to keep her area looking good and how proud she was of the work she performed. But Rita also shared that she feels customers are rude and inconsiderate because of where she works. And, she said they always mess up her department. As I listened to Rita’s story, I was reminded of Nickel and Dimed and Ehrenreich’s (2001) recollection of how possessive she became of her clothing section while working for minimum wage at Wal-Mart. The following is Rita’s story of feeling visibly invisible.

Rita works in the shoe department at K-Mart where she only gets between 12-15 hours a week. She is proud that she is working and tries to do a good job—the shoes are her responsibility and she takes that responsibility very seriously.

“People make a mess when they try on shoes and they just leave them on the floor and walk off without making any attempt to put them back on the shelf. They are lazy and inconsiderate of people in our positions and think we have job security as long as we have to pick up after them. They think we’re lucky to have these jobs.”

(Patient interview)

Rita further explained her surprise at seeing one of the CHP doctors shopping at K-Mart and expressed how delighted she was that he would recognize and speak to someone like her.

There was one time when I was working in K-Mart and heard someone say hello. I turned around and saw it was Dr. Smith from the clinic. Him and one of his daughters was shopping in K-Mart. I just couldn’t believe he would recognize me.
outside his office and in the K-Mart shoe department of all places! (Patient interview)

Unlike the invisibility cloak that gives Harry Potter the magical and advantageous ability to remain invisible to those who would do him harm, those wearing the invisibility cloak of poverty straddle the abyss of being (in)visibly visible to all. For example, their invisibility can place them in a situation where they must seek food stamps to help feed their families. Their invisibility can make it necessary to stand in food lines or to visit food pantries to supplement what insufficient food stamps do not cover. Their invisibility can force them to ask for medical cards or to be placed in a heating assistance program. This very public uncloaking of invisibility, of asking for help from strangers, can be shameful, stigmatizing, and demoralizing to those who must put the growling of their stomachs and the growing mound of unpaid bills ahead of cultural underpinnings and their wounded pride.

Health care is another arena in which many poor people are treated as being invisible, even when they break outside their cultural and economic comfort zone to seek medical attention. There are a number of ways the patients I spoke with recalled being rendered (in)visible during the course of their medical treatment. Betty, a breast and cervical clinic patient, recalled how unworthy and invisible a nurse at a family practice clinic made her feel during an office visit.

I was in a doctor’s office and asked the nurse where I could go to get help with my medical bills. The nurse not only could not and would not help me, she would not even look me in the eyes. The nurse avoided eye contact and basically guided me back out into the waiting room. The receptionist behind the window motioned
me over, put her hand on my arm, and told me it would be alright. She then gave me a list of possible places to contact for treatment. I started crying because the receptionist made me feel important and not invisible. (Patient interview)

Patients also responded that they often were not treated as a human being, but just as another number on a medical chart. Wendy remembered how (in)visible she felt during her last doctor’s office visit when she was treated as a number rather than a name. As she explained, “At the doctor’s office they just take you in, take your blood pressure—they don’t even know your name. They don’t even know your name” (patient interview).

When describing how socioeconomic and cultural traditions impact Appalachian women’s attempts to seek out health care, Gina (CHP staff) offered the following philosophy about (in)visibility based on her observations from working in the free clinics.

I think that these women have a tendency to hide their problems unless they have someone they are connected to talk to about them or have someone they feel they can trust. They’re not used to having people listen to them and care about their health. (Staff interview)

During our conversation, Gina struggled at times to find the appropriate words (she did not want to sound condescending or judgmental) to explain the matter-of-fact demeanor, the family dynamics, and the array of health issues faced by many of the young Appalachian women she sees during patient intake. Since she is about the same age as many of these women (Gina is 23), she used herself as a gauge to compare the extreme differences in lifestyles and opportunities.

One thing that has been interesting for me is not just being exposed to this population, but being exposed to women my age in this population. Most of them
have two or three kids by now and a lot of them that come to the clinics have depression, anxiety, drug abuse, nicotine addiction—they’re living lives that are totally foreign to me—lives that you know are a series of educational choice making and that’s encouraged by family values, and that’s encouraged by good friends. It just goes to show that when resources like family and education are in place, you’re going to get a totally different outcome. It’s really hard for me to sit here and enter data and read some of the daily reports from some of the girls that are my age—oh my God—they’ve lived five lifetimes in comparison to me. They make me feel like a baby. (Staff interview)

The correlation between living in poverty and seldom seeking medical care due to lack of insurance or money seems fairly transparent. However, what might not be as obvious are the residual effects on individuals who have been living for years without medical attention. By the time many of these patients are seen by a physician, they present not one singular health issue, but an accumulation of degenerative and/or multiple health issues. To determine which health issue is the most pressing or life threatening, medical personnel must perform patient triage before they can start a treatment regiment. The necessity of using patient triage is discussed in the following section.

Patient Triage: Determining What Should be Treated First

In his book on poverty, Shipler (2004) noted, “Poverty leads to health and housing problems. Poor health and housing lead to cognitive deficiencies and school problems. Educational failure leads to poverty” (p. 228). Concomitantly, the themes examined in this chapter intersect, and the ripples that emanate from one set of issues or circumstances impact the others in the domino effect described by Shipler. Much like
emergency medical workers perform triage at a disaster site to determine which patients need medical care first, the CHP staff must regularly perform triage on their patients because of the myriad medical, personal, and socioeconomic issues their patients bring to the table. As Stuart and Lieberman (2002) submitted, “neither illness nor health can be understood as purely personal events but must be seen in the context of family and cultural ties” (p. 15).

While performing the triage, CHP staff sift through their patients’ chaotic stories in an attempt to uncover the root cause(s) of their illness(es). The following story shared by Melissa, a nurse practitioner, illustrates the multiple layers of underlying issues that effective triage can reveal.

One woman that I examined—her blood pressure was sky high—nearly stroke level. She was overweight and she smoked so that was two strikes against her. When I asked her to tell me what was going on in her life, I found out that her husband had been in an accident and she was having to care for him. He was getting some disability, but without a full paycheck, she was having a tough time making ends meet. In addition to her husband, she was caring for her live-in mother who was recovering from a stroke and she was the primary care-giver for her 15 year-old daughter’s baby. This woman lived in absolute chaos—no wonder she smoked and had high blood pressure! So I told her she had a lot to work on because, although medication was the first step, medicine alone was not enough to lower her blood pressure. She needed to quit smoking and she needed to lose weight and she needed to eliminate some of the stressors from her life. But what does she deal with first? All of these issues impact her blood pressure, but I could
only help with medical part of her life. I gave her a prescription for blood pressure medicine and made a follow-up appointment at the residency clinic. I also gave her pamphlets on quitting smoking and about dieting and exercise—that’s all I could do and I know that’s not nearly enough. (Field notes)

As Frank (1995) noted, “in the lives of those living in extreme poverty, illness cannot be other than chaos” (p. 114). Chaos narratives are hard to hear because they remind us how easily we could be overwhelmed and pulled under by a chain of unfortunate events or trauma in our lives. For those patients living in chaos, care givers must chip away at the seemingly bottomless list of contributing factors that lead to their chief complaint of illness. When treating a diabetic patient, for example, medical staff must prescribe medication and coach about proper nutrition even when they know their patients cannot buy the food, and often the medication, they need to regulate their blood sugar. When treating patients for asthma or bronchitis that is caused by years of smoking, medical staff must treat the illness while encouraging patients to stop the behavior contributing to the illness. The cycle of these chaotic stories of illness continues generation after generation after generation and patient after patient after patient.

The heartbreaking aspect of triage is that many of the issues driving the health concern or illness cannot be solved solely by medical intervention. The chaos story “presupposes lack of control, and the ill person’s loss of control is complemented by medicine’s inability to control the disease” (Frank, 1995, p. 100). The following conversation between a patient and nurse practitioner illustrates how this lack of and loss of control haunts (and perhaps taunts) both the patient and the care giver.
During an examination Carol invited Kathy to “tell me about what’s going on with you.” Kathy told her that she had a lot of stress going on in her life. She had lost her job and then lost her house and had to declare bankruptcy. Her son, daughter-in-law, and grandchildren had been living in the house and now they have nowhere to live. Kathy is now living with her boyfriend, but doesn’t know how long that will last before she is homeless as well. After Kathy left, Carol confided in me that she hears this type of story all too often from the women she treats. “Unfortunately,” Carol remarked, “all the free medical care in the world isn’t going to help provide them with food and shelter.” (Field notes)

During another free medical clinic, the nurse and nurse practitioner had both interviewed a patient to chart his medical and personal history. They had, they believed, gotten a comprehensive overview from their triage. However, as Danielle (CHP nurse) recalled, they did not dig deeply enough to acquire a very vital piece of information.

We had this one patient come in that had some issues going on—had actually years ago been stabbed—we didn’t know he’d been stabbed—he had an injury that he really didn’t go into with me, didn’t go into it with Carol. I did my thing and Carol did her thing and then he went in with Dr. Roberts just to close things up. During the conversation, Dr. Roberts sat down in front of the patient and he said something about the scar on the patient’s neck. All he said to the gentleman was “tell me about that” and from that the patient spilled out the fact that his girlfriend had attacked him with a knife and he was life flighted to Columbus. Dr. Roberts looked at Carol and me and said, “Did you know this?” We said no. All I heard was that he had a stroke and he told Carol the same thing. When he talked
to Dr. Roberts, we found out that his stroke had been induced by the stabbing.

(Staff interview)

Of course, performing triage and administering care is not possible if there are no patients to treat. One of the barriers that staff regularly encounters is in getting patients to take advantage of the free medical clinics either as walk-ons or through prescheduled appointments. The staff has tried numerous ways to get the word out to prospective patients, including public service announcements in local newspapers and on local radio, posting flyers on bulletin boards in churches, senior centers, and post offices, collaborating with local churches and food banks, and through word of mouth. They have established set clinic schedules, hours of operation, and locations to make obtaining care easier. However, the mobile clinic still frequently sits at site locations with very few patients coming on board for treatment. An exception to this rule is the free diabetes clinics which are filled beyond capacity.

One of my questions during interviews with patients and staff was geared towards eliciting their opinions about why more Appalachian people (including patients’ families and friends) did not seek any type of medical care. A second question sought to elicit their opinions about why more people did not take advantage of the free CHP medical clinics given the level of poverty and need in the area. Several barriers were the most frequently identified reasons for not seeking medical care, either from a traditional source or from the free clinics. Interestingly, many of the barriers identified for not seeking medical care at all and for not seeking free care are very similar. One noted exception voiced by many of the patients was the issue of stigma and pride associated with accepting a “handout” for free medical care. The barriers identified for the sporadic use
of these badly needed services are explored below in the discussion of the second theme, *barriers to care*.

**Barriers to Care: Falling Through the Cracks**

Frank (1995, 2004) believed that illness, tragedy and trauma create a space and a call for stories. The majority of the patients I observed or interviewed were women and most of them had compelling stories to explain why or how they needed free or reduced medical care. The most commonly cited reasons for not seeking medical care include the lack of money and the lack of insurance or the loss of insurance. The following stories illustrate the precarious financial positions these women find themselves in and how that impacts their acquisition of, and access to, medical care.

Some patients find themselves, and often their family members, falling through the cracks as they struggle to pull themselves out of the poverty cycle. Although gainfully employed, they still cannot afford health insurance; they cannot afford standard fees for medical care; and they cannot afford prescribed medications. Holly, a patient who was seen in a free care clinic, did not grow up in poverty but was plunged there when she lost her job and her husband became ill with Hepatitis C. Holly described how both she and her husband are falling through the cracks and struggling with their health issues without the benefit of insurance and a steady income.

I haven’t had a real medical exam since I got laid off and lost my insurance in 2003. I haven’t been able to find full-time employment and cannot afford to buy insurance with the types of intermittent jobs that I have been able to get. My husband has Hepatitis C, and I was tested for exposure to the disease. However, without insurance the doctors won’t do further tests to see if I am positive or to
see how my husband is doing—no insurance equals no tests. My husband was on medication for the disease when I had insurance, but he’s not on anything now because we can’t afford the drugs. (Patient interview)

Even though their take-home pay falls within the guidelines that qualifies them to receive some basic free or reduced health care, patients often make just a little too much to qualify for the next level of free medical care. The following story about Diana, a breast and cervical screening patient, epitomizes what it is like to live in health care purgatory.

Diana works full time but does not have health insurance. Her husband had a stroke two years ago and has not been able to work since. He used to have two jobs and so they went from three incomes to just her income. They also lost their insurance when her husband had to stop working. Then Diana became ill and ran up a large hospital bill. “The harder I work, the poorer I become” is how she described their circumstances. Julie, a CHP nurse coordinator, explained that Diana’s income was low enough that she qualified for the free breast and cervical cancer screenings. However, she makes just enough over the poverty level that there is no mechanism in place to pay for her medical care if her pap or mammogram test results come back positive. “Diana is another one of those women who fall through the cracks.” (Patient interview; field notes)

Many of the patients are widowed and have no health benefits through their spouse’s pension, they are widowed and are not old enough to draw pensions or get Medicaid, or their spouse lost health insurance coverage when he retired. Sandra, for example, lost her insurance when her husband retired after 40 years. They had good
health insurance while he was employed, but for her to be included on his retirement insurance is just too expensive. So, Sandra does not go to the doctor unless there is something badly wrong. (Patient interview)

Katherine, who has had no insurance coverage since her husband died, also does not go to the doctor unless she is extremely sick. She realizes that, without preventative care, women are placing themselves in jeopardy for more serious medical problems. But, as she explained, “I realize that women should go more often for health reasons and so they can catch stuff early and get treated. But most can’t afford the doctor and they certainly can’t afford any treatment needed anyway” (patient interview).

In some situations, patients reported that they opt to either pretend they are not sick or hope that, if they ignore the symptoms and the pain long enough, the problem will just go away. If they cannot afford to pay for an office visit and the tests to see if they are sick, they certainly cannot afford the surgeries, medical treatment, or medication needed to get better. Carol, a CHP nurse practitioner, shared this story about a patient who had visited the free medical clinic the day before.

A lady yesterday had some heart arrhythmias and she has no health insurance. I asked her what her husband did and I got the story about how he got injured a year ago—fell off a ladder on the job and got hurt pretty bad and was no longer able to work. Two months later they took his health insurance away, and consequently, hers too. What I see mainly is that these women don’t have any insurance. Their whole way of dealing with things, I think, is “well I don’t have any medicine; I’m just going to keep on going and doing the best I can unless there’s a super emergency, unless I absolutely have to go.” If they’re depressed,
they feel that they can’t afford any medicine for that so they just keep going. If they have a pain in their stomach, they’ll just keep going until they can’t move and then maybe they’ll go to the ER. Some women who’ve had breast lumps think “What’s the point? I won’t be able to afford the surgery to have it removed anyway so what’s the point in going?” It’s almost like a hopeless feeling that you hear over and over again—“I can’t afford it; I can’t afford it.” (Personal interview)

In other cases, patients have gotten so far into debt after experiencing a comprehensive illness that they have had to forego follow-up care and medication. Peggy shared the following story about her situation after suffering a heart attack in 2007.

When I had my heart attack, I ran up a $98,000 hospital bill which I can’t pay. I was supposed to go back to the specialist for a check up but could not afford the $150 up front fee just to see the doctor—so, I just didn’t go back. Since I can’t afford to go back to the specialist and I can’t afford to pay for my heart medicine, I’m not taking any medication for my heart. I haven’t seen any doctor since my heart attack for any medical issues until today. (Patient interview)

A recent article in *The Athens Messenger* (2008, October 23) noted that the failing economy is leading many Americans who are covered by health insurance into skipping doctor appointments and routine or preventative care such as mammograms and pap tests. The first priority for the people interviewed in the story was putting food on their tables and making their house payments. The rising co-pays and out-of-pocket expenses are simply making non-emergency medical care a lower priority. If people with jobs and
medical insurance are feeling the sting of seeking medical care, one can only imagine how people feel who have neither option available to them.

A second barrier that keeps patients from using the free medical services is their lack of knowledge about what resources are available to them, where the resources are located, or how much money they can make and still fall within the poverty guidelines. Many patients assume that if they are working or receiving some type of pension or aid, they do not qualify for free medical care. In the following section, patients Betty and Jane explain how they believe a lack of knowledge inhibits people from using free medical services.

*Lack of knowledge about resources.* Betty believes that the working poor are impacted by the health crisis and the lack of insurance more than people who have always been in the system because the working poor don’t have the mindset to look for free treatment; they don’t know the system, and they do not know how to go about getting free services. Even after she heard about the free medical clinics, Betty had a difficult time finding out how to go about getting enrolled in the programs.

I called the medical college to try and find free medical care and got passed around until I finally got someone who knew about the clinics. Had I not been scared and desperate, I would have probably given up long before I found someone to help me. It’s not emotionally easy to ask for free services when you have been used to being self sufficient and paying your own way. (Patient interview)

Jane says there are a lot of people who fall through the cracks of health care because the poverty guidelines, like the minimum wage guidelines, do not adequately
depict the cost of living. Like Betty, Jane also feels that many people do not know what resources are available to them and they do not have any idea how to find out what is out there. Jane also believes that a number of women are kept away from the clinics because they don’t know the guidelines for qualifying for free care. “They think if they’ve got a job, they don’t qualify for a free clinic and that’s just not always true” (patient interview).

Another barrier, I believe, to patients using the free services comes with not a lack of knowledge about the services, but a lack of knowledge about how to complete the large amount of paperwork that must be done before they can be seen. For example, the women who are scheduled for breast and cervical screenings are sent a large envelope of papers to complete about their medical history and income. They are required to bring these completed papers, and often proof of income, with them to their appointment. Walk-on patients must be able to complete all the necessary paperwork while they wait for patient intake. When you consider the level of reading skills many of the patients have (several patients visibly struggled with completing and understanding the forms and had to request assistance from staff members) and the private and closed nature of Appalachian people, I cannot help but wonder if this deluge of paperwork inhibits patients from using the services.

Once patients know where the clinics are being held and make plans to be seen, the next obstacle many must face is how to get to the clinic locations. In the following section, I discuss the barrier of mobility.

*Mobility.* Julie, a nurse coordinator, knows the difficulty many of her patients face in just physically getting to a clinic site for treatment. She shared the following observation: “There are a lot of barriers to people using our services. Mobility is one—
some people just don’t have transportation and I imagine it’s gonna get worse with the cost of gas. Here are people that are low income and Medicaid, I mean that I’ve heard for years that’s why they don’t have the gas money to get to their doctor’s appointment. That’s gonna be worse; that’s going to make it harder on people” (field notes).

Many of the patients who use the CHP clinics do not have their own mode of transportation but must depend on the kindness of relatives or neighbors. This means, to use the free services, they must first find out where the clinics are located and then see if the date and time works into the schedule of the person who will be bringing them. They are then at the mercy of those people, and if something happens that their ride falls through, they miss out on their appointments. This is especially critical when they are being referred for other services that require them to stick to an appointment schedule.

Sally, a nurse coordinator, refers her patients to a number of different agencies for assistance. She constantly receives calls from the referring agencies telling her that a certain patient cannot be referred again because he/she missed their appointments. Sally shared the following concerns and experiences with the barrier of mobility: “A lot of people can’t get to referral services. Those are the ones I think about—they couldn’t go because they didn’t have a car and the agency said you’re out because you’ve missed three appointments” (staff interview).

Even for those who do have their own transportation, the rising costs of fuel make the distance between where they live and the closest clinic impossible to afford. Although the CHP can offer $10 gas vouchers to patients who are in the worst financial straits or who live the farthest away, at $4.00 per gallon for gas, the vouchers barely cover the cost of driving one way. Several times during my observations, members of the CHP would
take turns driving to a patient’s home to drop off the gas voucher because the patient could not afford enough gas to even get to a clinic to pick up the voucher.

The CHP staff also frequently use their personal time and vehicles to deliver prescriptions or medication to patients who cannot or do not have a mechanism for obtaining the supplies on their own. Dusty, a nurse coordinator, recalled the following patient who was out of insulin and who had neither the money to pay for the insulin nor the gas money to come and pick up a free supply to tide her over.

I met this woman at the Dairy Queen to take her some insulin because she was clear out. This woman tells me “I’ll be in the Dairy Queen parking lot and you’ll know me, my car is—I don’t know if it’s gray or silver—but you’ll know me because the rearview mirrors are all knocked off.” As soon as I pulled in, I realized why she couldn’t tell if the car was silver or gray because it was old and the paint was so worn off I couldn’t tell you whether it was silver or gray either. The rearview mirrors looked like somebody hit them with a ball bat—they were gone. I get out of my car and I take the insulin over to her. Her entire door is duct taped together. These people have it rough and you don’t realize it until you really, really see how rough it is. I mean her car is duct taped together. Isn’t that sad? (Staff interview)

Dusty’s story about the condition of the patient’s car illustrates the hard conditions that many of the CHP patients endure. As Gina (CHP staff) noted, these people have far more to worry about than their health. “Other things are more important in this culture then healthcare. They’ve got other worries to attend to—bills, giving money to their kids, they don’t have transportation—it’s hard for them to get access to
transportation or to even know care is out there—especially when they’re so isolated at home” (staff interview).

The barrier of mobility prevents many patients from either seeking care or from keeping referral appointments. The lack of their own transportation and the lack of money to operate that transportation are also factors. In the following section, I look at a barrier which is closely related to mobility—the barrier of flexibility.

*Flexibility.* As I mentioned when discussing the barrier of mobility, even when patients are able to find a kind neighbor or relative to bring them to a clinic, they must be flexible to work around their providers’ schedules. Since most clinics operate only through the week days and only during day-time hours (the diabetes clinic is the only exception), this often limits patients in seeking care.

Another barrier to receiving free health care is the lack of flexibility many of the patients have in meshing their schedules (spouse work schedule, child care, their work schedule) with that of the scheduled clinic days and hours. Yet another issue that arises frequently is scheduling follow-up appointments or additional testing at other medical facilities. This tension was apparent when Julie, a nurse coordinator, returned from scheduling follow-up testing for Terry.

Julie returned from using the phone at the health department and told Terry that she had scheduled her free mammogram for 1:45 the following Tuesday. Terry’s face fell and she started twisting her hands together. “What’s wrong,” asked Julie? Is there a problem with your appointment?” Almost in tears, Terry explained that she would have to ask off work again to get her mammogram. And, since the appointment is not until 1:45, she won’t be able to start work until at least 3:30.
This means she can’t get a full 8 hours pay that day and she can’t afford to miss that many hours. Julie patted Terry on the shoulder and said she would work to reschedule the appointment at a better time. Julie later told me that this is a typical clash between needing medical screening but not being able to either get time off from work or not being able to miss the pay from not working. “Our women can’t even afford free medical care.” (Field notes)

Another barrier that patients face involves a multitude of fear factors. These factors include the fear of facing medical issues they do not understand, the fear of dealing with the bureaucracy that accompanies treatment regimens, the fear of how they will pay for treatment, and the fear that comes with asking for help. In the next section, patients reveal how their fears influence health care options.

_Fear._ The fear of medical care is a huge barrier to a population used to taking care of their own and distrusting the bureaucracy that accompanies asking for free medical care. As Ruth’s story below illustrates, sometimes the fear of the unknown is preferable to knowing you have an acute or deadly illness.

Ruth thinks it is important to come in for screenings because of family history. Her sister’s daughter died from breast cancer as did her father and her husband. Ruth’s sister, whose daughter died, has never had an exam. She says what will be, will be. Ruth thinks her sister’s attitude is typical of Appalachian women—the fear of the truth is worse than the truth. They would rather not know—their attitude is “if I’ve got it, I’ve got it and knowing won’t make it any different.”

(Patient interview)
Wendy echoed Ruth’s sentiments about the women in her family being fearful of finding out they have cancer. Wendy tried to talk her cousin into coming with her when she received her breast and cervical exam, but Beth refused. Wendy explained why she believes women take this stance on health care: “Women don’t have testing done because they don’t want to hear what doctors have to say. My cousin, Beth, that’s what she told me. She’d rather not know” (patient interview).

Mary had a similar experience when she tried to get a friend to come with her to the B&C clinic. Mary said she tried reasoning with her friend by telling her that early detection was the key to surviving cancer. However, her friend still refused to come because she believes, “If they find cancer, then what? I ain’t got no money to pay to take care of it—I just don’t need to know and have one more thing to worry about” (patient interview).

The inability to pay for extended treatment in the event of a cancer diagnosis was also a frequently cited fear. For example, Denice believes that women do not come in for treatment because “they are afraid there is something wrong and their problems would escalate in the aftermath if they couldn’t get further financial assistance” (patient interview). Amanda, too, offered that she thought cost was a factor, and even with the option of the free clinic, women are still scared that if they find out they have cancer they will die because they cannot afford to do anything about it (patient interview).

Yet, for other women, fear comes in the form of denial—cancer will never happen to me so I do not need to get checked or to do self breast exams. At a local community center health fair, a breast cancer survivor shared her experience of denial. Marty’s speech was especially powerful to the women in attendance because she does not live in
poverty—she works in the health care field. Marty’s example was both a wake-up call about the importance of being screened and a testament that breast cancer was not a death sentence.

Marty started her speech by saying, “For me, having cancer was like being on an emotional rollercoaster. My sister had breast cancer and I went back and forth from thinking it couldn’t happen to me, to it will most likely happen to me. I’ve always had fibrous breasts, so I didn’t think I would be able to notice a lump or any change. I was wrong.” (Field notes)

In a couple of cases, the fear of having or getting a life-threatening disease actually brought women in for screenings. Amanda, a 30-year old woman who was being screened for breast and cervical cancer, was able to convince her mother to come with her. As Amanda explained, “My mom is in her 50s and I brought her with me today for a screening. My bout with cancer scared her and made her realize the importance of screenings. She has never been screened before today” (patient interview).

Rhonda was also scared into making an appointment for the breast and cervical screening clinic due to her grandmother’s experience with cancer: “It’s been eight years since I’ve had a pap and breast exam, but my grandmother is going through her second remission with breast cancer and that has me scared into getting checked” (patient interview).

One of the biggest reasons for not asking for free medical care rests with the barriers of stigma and pride. These barriers are explored in the following section.
"Stigma and Pride."

The poverty of our century is unlike that of any other. It is not, as poverty was before, the result of natural scarcity, but of a set of priorities imposed upon the rest of the world by the rich. Consequently, the modern poor are not pitied...but written off as trash. The twentieth-century consumer economy has produced the first culture for which a beggar is a reminder of nothing. (Berger, 1992, p. 572)

Lindemann-Nelson (2001) believed a person’s identity is damaged when they endorse a dominant group’s dismissive or exploitative understanding of their group or when a powerful group views members of a less powerful group as being unworthy of full moral respect. The treatment of those who are more powerful toward those living in poverty often contributes to stigmatization and, subsequently, damaged identities as they feel (in)visible and unworthy. Many of the patients interviewed during field work were concerned that the CHP medical staff knew that just because they were accepting free medical care did not mean they were lazy and out to beat the system.

One of the patients, Judy, made sure that I knew she worked on a farm for room and board—that she was not unemployed. Judy feared that we would think that she was just lazy because that’s how poor people are treated. During my interview with her, Judy emphasized several times that she is a hard worker, that she is not lazy, and that farm work is hard. She expressed her fear that the medical staff would think, “Here comes a lazy-assed woman who won’t get a job.” I reassured Judy that many of the women we saw were in similar circumstances and that I had yet to meet a lazy-assed woman in any of the clinics. (Patient interview)
Sometimes women will not come into the free clinics because of the stigma they believe is attached to taking handouts. Pride is another factor that keeps some women from seeking free medical care. As Julie, a nurse coordinator, explained:

And there’s stigma. I’ve seen this in different places, you know. It’s like I’m not going to have my pap test done in a free clinic. We had a patient yesterday that was really uncomfortable and was embarrassed to come because she hated to say that she needed these types of services. It was a pride thing and I try to get that dismissed as soon as I can. I try to make people feel it’s OK to come and use these services and to not feel bad because they need them. (Staff interview)

When I asked Jane, a breast and cervical screening patient, why she thought more women did not take advantage of the free clinics, she reiterated Julie’s sentiments about Appalachian pride.

It’s humbling accepting free medical services. I appreciate it and I’m very thankful that there is such a program. But I think that might be the reason people don’t go to get the services because it wounds their pride in some way to accept a handout. I think that’s characteristic of this whole area. People have their pride in taking care of themselves and in taking care of their own. (Patient interview)

Shipler (2004) argued that the poor are caught between American hedonism and its dictum that the poor are supposed to sacrifice, suffer, and not buy any objects (cell phones, video games, cable TV, etc.) that are considered fun or luxury items. Carol’s patient, Judy, had obviously received criticism about being poor and wasting her money on cigarettes.
Judy told Carol how embarrassed she was to have to use the free services. When Carol asked if Judy was still smoking, she replied that she was, but stressed several times that she rolled her own because it was cheaper. Judy told Carol she didn’t want her to think she was seeking free medical care while spending money on buying packaged cigarettes. Carol explained that Judy brought it up like she was being judged when nobody had said anything about her spending money on smoking. “My question about smoking was strictly health related and was not meant to be monetarily judgmental.” (Field notes)

The examples shared above are by no means the only instances where the women I observed and interviewed tried to justify their use of free medical care. For instance, women shared that their husband had just left them or that they were recently divorced or widowed. Several women shared that they had recently been laid off and were having problems finding another job. For many, like April who shared the following story with me, it seemed important that we know they were not just sitting around hoping that life would improve. April emphasized that she was trying to dig herself back out of the hole of poverty for not only her, but for her entire family.

April and her husband were both employed at the same company and both were locked out and lost their jobs and insurance at the same time. “We have a 14-year old son who is struggling with not being able to have the material possessions he is used to. We simply cannot buy him what we were used to purchasing because we do not have enough money to even pay our bills. I’m attending Rio Grande in the respiratory therapy courses, and I’m taking 20 hours to catch up. I also care for my grandmother to make extra money but realize that my grandmother won’t
live forever so this income is not guaranteed. I’m not going to quit trying though, I may have to accept a hand out right now, but I’m going to change that for all of us.” (Patient interview)

In response to my question about why they believed so many of their Appalachian friends and family would not or did not seek free medical care, the women consistently responded that they felt it was a pride issue. Terry, widowed and unemployed, was a first-time patient on the breast and cervical cancer screening clinic. Even though she had previously heard about the clinic from a flyer posted at Kroger, this is the first time she has used the clinic because of embarrassment and pride. However, she found a lump in her breast and got scared enough to put her health before her pride.

Sometimes the barrier to using free services comes from within the family. For example, Carol shared the story of a patient she had recently treated at a breast and cervical screening clinic.

While we were eating lunch, Carol told me about a patient that she had recently who had insurance with a $5,000 deductible. Her husband would not let her accept a free screening mammogram through the Susan B. Komen grant because he wasn’t taking a hand out. The situation was particularly upsetting for Carol because this woman went ahead and did the mammogram herself and paid for it and the test showed an abnormality. She has since had an ultrasound and aspiration of the lump and is waiting for the test results. Carol could not believe the husband denied his wife the free mammogram because of pride. (Field notes) Individual pride and the stigma from being looked down upon can keep people who desperately need medical attention from reaching out. Because, as Goffman (1963)
suggested, “personal identity can and does play a structured, routine, standardized role in social organization” (p. 57). So, as I interviewed each patient, I encouraged them to talk with their friends, neighbors, and relatives about the Community Health Program and to assure them that the staff is welcoming and nonjudgmental. I also encouraged each patient to bring one person with them the next time they visited a mobile clinic. Because word of mouth is important and carries weight in the Appalachian culture, I hoped the encouragement from someone (such as a relative, neighbor, or a friend) trusted and in a similar situation would help to break down the barrier of stigma and pride and eventually the damaged identities of many will begin to knit and repair.

The last barrier to care identified by patients and staff was that of the health legacies that had been passed down from one generation to another. Patients often voiced a nonchalant attitude of “if it ain’t broke, then don’t fix it.”

*Health Legacies: If it Ain’t Broke, Don’t Fix it.*

*It was the spring of my fourth grade year and my nephew, Terry, had gotten a new red bicycle for his birthday in May. My sister brought the bike with them when they came for a visit from Columbus. I was excited to see them for a couple of reasons—one was because my sister was giving me Terry’s old bike—the first bike I had ever had. The second reason I was excited was because Terry was going to let me ride his new bike—I had never ridden a new bike. I was so excited because the new bike had a speedometer on the handle bars and I couldn’t wait to see how fast I could fly down our gravel road. I was something of a dare devil!*
I rode the bicycle sedately up the road over the crest of the little hill so I could get up good speed coming back down. I kicked off and away I flew down the road towards my house. I was pumping furiously trying to get the speedometer to at least 30 miles per hour and I was almost there. Then tragedy struck—the bike slid on a big pile of gravel and down I went. The next thing I remember was Terry trying to get me up, but my left leg was caught between the boy’s bar on the seat and the road. Somehow he finally managed to pull my leg free, get me up from the road, and drag me into the house. I was sobbing from the pain of the gravel embedded in my face, hands, and knees and from the pain radiating from my right arm which I realized I couldn’t move. My mom sat me in a kitchen chair and started washing away the blood and picking out gravel. I must have passed out as I remember a black cloud rolling over me and nothing else for a bit. The end result was a horribly bruised chest, a blackened and numbed calf on my left leg, and an arm that I wore in a sling for about three weeks. I was never taken to the doctor—we could not afford to go and that’s just not something our family did.

Talk about a health legacy—the injuries from that bicycle wreck are still with me 42 years later. I still have a numb spot on my calf, my right hand and fingers go numb, and I have nerve damage in my wrist. A couple of doctors have told me that there was a good chance my wrist was broken that day. I truly don’t think my mom thought she was doing anything wrong that might have long-term repercussions—she was taking care of me with the resources and the knowledge she had available. It’s just how we lived.
During my interview with Carol, a CHP nurse practitioner, I asked her if she ever used stories to help patients understand medical instructions or concepts. Carol replied that she thought patients could really relate if care givers could connect what the patient was experiencing by sharing something personal that their parents or their children had experienced. Carol also explained that stories could serve as an instructional tool, especially in a culture where misinformation about medical treatment is passed down through generations. The following excerpt from our interview provides insight into how care providers must deal with such health legacies.

Karen: Do you think sharing stories is an instructional tool? Do you think sharing helps you bond with people or to put them more at ease?

Carol: I think it’s helpful. I think most of the people that we see are just so grateful and are just down to earth and are not real interested in technical research studies about things, but yet you don’t want to perpetuate old wives tales and things that don’t work. I think that everyone is an individual and you have to look at what teaching moments or opportunities there are. I respect people’s traditional and ethnic kind of history, so I don’t want to be too critical. But yet, if you hear of somebody doing things that are dangerous or are not appropriate, it’s a good time for teaching a little bit of alternatives they can use.

Karen: How do you approach patients when they are telling you that grandma did or said this or great grandma did this and that’s how it is—we know this works because we’ve been doing it for years and nobody has died yet.
What approach do you take to say to that person, “I understand that this is what happens in your family, but….”

Carol: I think it’s important that if you hear somebody is doing something really dangerous to explain it and to educate them. But if it’s not going to hurt anybody—blowing smoke in someone’s ear for an earache—I don’t mess with that. I might give them a little something else they can try, but I’m not going to tell them that what they’re doing is wrong.

Karen: So you would be careful not to offend them while educating them that there might be a better way or at least something else they might want to think about trying if that doesn’t work?

Carol: Right, if blowing smoke doesn’t work, you might think about trying this.

Often the health legacies that patients live by do not involve home remedies that have been handed down by elders, but instead center on the attitude of “if it ain’t broke, don’t fix it.” For example, Rita only uses the CHP services every once in awhile because she has always been healthy. She just doesn’t see the need to come to the doctor when nothing is wrong (patient interview).

Debbie told Julie that it had been a long time since she had a pap or mammogram, but she was not concerned because she felt fine and was not having any problems. This seemed to be a typical response from patients who have not sought regular screening—I don’t need screening because I am not having any problems. Debbie shared that she finally decided to come in for screening only “because I’m getting older and starting to see some changes in my body—I thought it might be a good idea to get tests done because of potential problems” (patient interview).
Although Jane believes cost is a factor keeping women from seeking medical care, she also believes there is a deeper health legacy that has been passed down. As she explained:

I think that women don’t seek medical care either because they have no family history of illness so think nothing will happen to them or because they—because I think women don’t come in and get tested because they can’t afford it sure—but I also think they believe “I’m not going to get that, I’m not going to get cancer so I don’t need that care. There’s never been anything wrong in my family; I don’t know anybody’s that had that kind of cancer so why should I go?”

Until you have some personal association with cancer, you don’t see the need, you don’t see it as important as it is. I think as human beings we rationalize our way through life and a lot of time something kind of has to hit us in the face before we take notice of it. I think that things like health for a lot of people who have never been sick in their lives, it just isn’t an issue—they don’t think about it—they just don’t think about it. (Patient interview)

Yet in other cases, the women I spoke with realized the need for preventative care and they tried to have annual exams on a regular basis if at all possible. However, they were often discouraged from seeking care by their spouse or other family members. Wendy described how her husband reacted when she told him she needed follow-up care for two specific health issues: “I don’t deny the situation (with high blood pressure and depression), my husband denies it. He says you know, you’re fine, you’ll be all right, just shut up sweetie pie. Which he’s right—I need to just shut up and let things go” (patient interview).
As the conversations with patients and staff indicate, providing medical services for an Appalachian population is not just as easy as “if you build it, they will come.” The barriers that negate or interrupt the flow of medical services might not be proportionately large in scope but they are still very real and they are very daunting. In the next section I discuss the third and final theme that acts as yet another barrier to dissuade patients from seeking initial or continuing medical care, *assembly line medicine*.

**Assembly Line Medicine: Like Changing Parts on a Car**

Dorothy, a breast and cervical cancer screening patient, thinks that part of the problem with doctors is that they are part of HMOs and that the HMOs drive the number of patients that have to be seen and they drive the amount of time doctors can spend with each patient. She calls this “assembly line medicine”. Dorothy described a former male physician’s technique of doing pap tests as “changing auto parts on a car” because he was rough and did not waste any time in making small talk or in trying to get you to relax (patient interview).

Dorothy’s experience is, unfortunately, one that we have all experienced if we have spent much time working our way through the medical mazes (Beck, 2001). What is different about the stories shared by Dorothy and the other women interviewed is that they believe they are subjected to routinized and sub-par care because of their socioeconomic status. They feel that physicians do not want to expend much time or energy on patients whose income stream limits the amount of reimbursement they will receive for services rendered. As Kathleen explained, “Doctors never have time; they rush you and don’t listen. Doctors also want money up front. If you don’t have $40, you don’t go to the doctor” (patient interview).
When I asked Evelyn if she could tell me about an experience with a doctor where she felt she not given an opportunity to tell her story, she recalled her last appointment with a doctor at a local clinic.

I had this doctor the last time at the hospital clinic and she seemed very disinterested in me. She didn’t ask me any questions, she didn’t take time to listen when I tried to tell her what was wrong, she didn’t respond to anything I told her. She seemed to be more interested in pushing medication at me then finding a reason for my symptoms. Then she went and forgot to even write me the prescription and I didn’t realize it until I got to the pharmacy. I called that doctor’s office and told them she had better call the prescription into the pharmacy and I meant right now. I’ll never go back there again the way I was treated. (Patient interview)

As part of my field observations, I spent a good deal of time observing at a physician’s office. This office serves many patients who are either low income or pay on a sliding-fee scale. I was excited to observe in their practice and to watch how they interacted with their patients because I knew they had initiated a number of programs geared toward their at-risk patients. Although I believe they are on the cutting edge in their approach to socialized medicine, I was shocked at how little face time the physicians actually gave their patients.

As I observed the physician-patient interaction, I noticed that neither Dr. Brandon nor Dr. Carey spent much time with their patients. The doctors were quickly in and out, often barely touching the patients. They spent little to no time making small talk or asking patients how they have been doing. The process seemed very robotized,
routinized, cold, and impersonal. The doctors were nice and both appeared very personable, but I could not help but think of quotas and the waiting room packed with patients. On the average, the perinatal nurse, Molly, spent much more time with the patients than the physicians did. I guess this is an example of what Dorothy called assembly line medicine. Since I was actually observing the work of the perinatal coordinator, I never got to see the interaction between the physicians and their regular paying customers. I could not help but wonder sadly if the face time and personal attention increased with the patient’s ability to pay.

Still other women recalled experiences they had with doctors who tuned them out, shut them down, or came across as smug or superior. Jeanette recalled such an encounter when she accompanied her mother to the doctor.

Doctors don’t give you the time of day—they are in and they are out. My mom’s doctor wouldn’t listen to her—he was all business and it was a waste of time to go to appointments because we didn’t know any more when we left than when we came. He was always rushed and we didn’t feel comfortable asking questions.

(Patient interview)

Jeanette believes that too often doctors treat patients, especially women patients, in a condescending, God-like manner. She further asserted that the older, traditional generation of women are more apt to buy into that God-like behavior and do not expect to have open communication with their physicians. Our conversation began with Jeanette sharing the following joke.

I have this joke I heard one time. Do you know the difference between God and doctors? God knows he’s not a doctor! I think that’s pretty fun, but I also
think there’s a lot of truth, that it’s true. I think that is the way many women in
the generation before me thought of doctors—and they were all men doctors
then—and they were God. Whatever they said. Well that’s typical of how
women think of their doctors. My mother-in-law who had this mastectomy,
her doctor was close to God, I mean she just revered the man. (Patient
interview)

Ruth, who used to work in a medical office, holds no false expectations of
receiving personalized medical care. From her experience, Ruth feels that physicians and
their staff in general do not really care how a patient is doing unless it relates to a specific
health issue. Ruth shared this take on the medical world and its treatment of patients:

It’s not important for a physician to ask me how I’m doing. When a doctor or
nursing staff ask a patient how they are doing, they really don’t want to know and
don’t expect or want an answer other than “I’m fine.” The “how are you doing”
question is a form of greeting and not a request for you to really tell them how
you’re doing. (Patient interview)

Kathy’s philosophy on how physicians should interact with their patients differs
entirely from the viewpoint held by Ruth. Kathy believes that doctors should care about
how their patients are doing and that it is important for them to LISTEN to everything as
they might miss something important that would help with the diagnosis or treatment. For
an example, Kathy shared a story about a doctor who kept asking her if she smoked even
though she kept denying she had ever smoked. Kathy felt the physician should have just
come right out and told her why she kept asking about the smoking. “Maybe if she had
shared why she thought I had smoked, I would not have felt like she thought I was lying.
She didn’t seem to understand that I had never smoked and her insistence that I had was making me scared that something was badly wrong.” Kathy also shared that she feels doctors are too quick to brush off patients and want to get to the main reason for the visit. “Often you need to tell them what led up to the problem and sometimes doctors just don’t seem interested in how you got to where you are” (patient interview).

Some physicians appear to view medicine like an assembly line production and adopt what Danielle, a nurse coordinator, called the “treat and street” method of care. For a population that already feels marginalized and stigmatized, the mentality of getting them in and out as quickly as possible does little to make them feel appreciated or well cared for. The philosophy of treat and street is further explored in the next section.

Quick care: Treat and street. More than one patient talked about having seen a doctor who limited them to one complaint per visit no matter what health issues they were experiencing. When I asked Danielle, a nurse coordinator, about CHP’s policy of treating multiple complaints, she explained that they try to dig deep to find out as much information about each patient as possible. A complete medical history and list of current complaints help the nurse practitioner in her triage and treatment protocols. Before joining the CHP, Danielle had worked at a traditional doctor’s office and saw plenty of this dismissive attitude towards patients. Unfortunately, Danielle further explained, not all the doctors who volunteer their services to the free clinic spend as much time with the patients as they should.

There are two physicians that I can think of that are here to treat whatever the patient came in for and don’t look at anything else. Their attitude is to let somebody else take care of that when we refer them to the residency clinic or
wherever we refer them. They’re “I’m here to take care of their blood pressure today—let’s get them in and get them out.” They have the mentality of treat and street them. Luckily they don’t work the van that often. (Staff interview)

Karla, an AmeriCorps staff member, has also witnessed physicians who have the treat and street mentality and who do not value taking time to talk with patients. She described what she had witnessed while shadowing one of the physicians that Danielle described. “I’ve shadowed another physician other than Dr. Roberts and he doesn’t spend as much time asking the patient questions. When we would get back to the room, he would mouth, like you know, like negatively criticizing the patient for talking so much. He just wanted to get them in and get them off the van” (staff interview).

Carol, a nurse practitioner, has worked in medical offices where patients were not always subjected to kind and considerate treatment. She explained her observations with a comparison of attitudes between caregivers in her current and former positions. “The people who work in this program all have the same philosophy and they’re kind. I’ve been in places where people are sarcastic and they roll their eyes—they’re just very impatient and not very understanding of the patients’ needs and situations” (staff interview).

Patients also recognize the importance of having their physician conduct a thorough assessment of their overall health. Betty would love to see more physicians who treated the whole person and not just the symptoms or the worst medical issue at that appointment. She believes that doctors need to learn about what is going on in the patient’s life that may be impacting his or her health because “you can’t make accurate determinations without knowing the root cause” (patient interview).
The final sub theme under *assembly line medicine* is the occurrence of patients who feel as though they received inferior or sub-par care because of their socioeconomic status. In the following section, patients and staff describe their experiences with care givers who they believe administered sub-par medical care.

*Sub-par care: “The poor people get the basement exam room.”* Carol, a nurse practitioner, and I were having lunch before the afternoon B&C clinic started. I was scheduled to have my annual exam the next day and she asked who my OB/GYN was. I told her who I used to go to and that I had actually changed to another doctor this year because I did not like the other doctor’s bedside manner. When I told her the physician’s name, Carol laughed and told me that she had plenty of experience with him when she used to work at the health department in that city. In fact, many of her clients used this doctor for their pregnancies and deliveries. She did not have a very high opinion of this physician because he would make his uninsured or Medicaid patients go to another location for exams and to deliver and would not let them visit him at his nice office. “The poor people get the basement exam rooms with linoleum and cheap furniture. People who are insured, like you and me, get nice furniture and carpeted rooms” (field notes).

Tina has also experienced sub-par care, she believes, largely based on her ability to pay. She currently sees a group of doctors at a practice in her community for heart-related problems. Since this is a group practice, she rarely sees the same doctor at each appointment so whomever she sees never knows her medical history. The last time she went to the office the place was packed, and when she started asking around, she found out that five other people had 11:00 appointments too. After a two-hour wait to see a doctor, he told her the computer was down and he could not treat her because he could
not access her medical history. Tina said that this practice treated people like garbage.

“They know we’re poor and we’re getting our appointments paid for by Medicaid or some other service. We’re not wealthy and they’re not going to make a lot of money from us. Therefore, they can schedule five appointments at 11:00 because our time is not valuable—we’re just garbage so it doesn’t matter how they treat us” (patient interview). Charon (2006) legitimized Tina’s complaint with her acknowledgement that “The skirmish about waiting room time might be taken seriously—we doctors are never on time, and our assumptions that patients do not mind being kept waiting is a pervasive and powerful message about differential worth” (p. 44).

Molly, a CHP nurse coordinator, offered her opinion as to why some doctors and nurses react negatively to some of their poorer patients.

We’re too quick to judge, we see someone who is maybe dressed a certain way, maybe has a tattoo or wouldn’t do what we would do or wouldn’t look or act like we would. We’re too quick to put a label on them and not listen to who they are. Most of the time there is not a comparison between the image we make in our minds and who that person is or what their needs are or what’s driven them to do what they are doing. (Staff interview)

When I asked Jane if she felt she had ever received sub-par care because of her socioeconomic situation, she broke down into tears as she recalled the treatment she had received during a biopsy.

I had a male doctor who did a biopsy because one of my paps came back positive. He did the biopsy and had me sitting up and he said, “Where’s the specimen?” He couldn’t find the tissue sample. He had a student there with him and he said “Well
I’m going to have to do this again.” I started shaking and doing some deep breathing and he said, “You seem really nervous. Don’t worry about this—this is just a little pinch. Don’t worry about it.” I just looked at him and I said “Excuse me, but if I said to you I’m just going to take a little teeny piece off the end of your penis, it really won’t hurt very much, what would you think? How would you feel?” And then, and then, they found the specimen after they did the second biopsy. He found the first one. It was on his glove!” (Patient interview)

Whether being subjected to the basement exam room, being subjected to unnecessary surgery due to carelessness, or having their valuable time and health concerns disregarded, many patients definitely felt the sting of receiving sub standard medical care at the hands of their physicians. As you can imagine, stories like this could drive women who already distrust the system and who already feel marginalized further away from seeking much needed medical care.

However, in order to transform health care for women like Betty, Jane, and Tina who have “historically had their bodily experiences defined, categorized, and encapsulated through narratives structured by the patriarchal medical system” (Das Gupta & Hurst, 2007, p. 4), such stories must be brought out into the open and discussed. Indeed, as Van Manen (1990) suggested, “All recollections of experiences, reflections on experiences, descriptions of experiences, taped interviews about experiences, or transcribed conversations about experiences are already transformations [emphasis in original] of those experiences” (p. 54). These stories and experiences are invaluable transformational learning tools to all lest we forget that people living in poverty need and deserve competent, efficient medical care too.
Summary

In this chapter I explored the storying of health in the midst of Appalachian poverty—an area that one Community Health staff member called “the skeleton in the poverty closet of the United States”. The majority of patients I observed and interviewed were women, and the majority of these women live on meager sums of money from pensions, survivors’ benefits, unemployment, or low-paying jobs. Because they are struggling just to pay their monthly bills and to put food on the table, health insurance, preventative or regular doctor visits, and life-sustaining medications are luxuries these women frequently do without.

This population is often (in)visible to mainstream society and are frequently ostracized as being lazy and uneducated and are often treated like something to be shunned or kept hidden away. Their socioeconomic circumstances, coupled with their cultural and traditional heritage, regularly place them in precarious positions that separate them from receiving much needed help. When they do reach out for assistance, however, they are forced from (in)visibility and thrust in the very public arena of visibility—whether it is from standing in line to receive food rations, using food stamps at a grocery store, or seeking free medical care.

The patients and CHP staff that I interviewed identified several barriers that make it difficult, if not impossible, for this (in)visible population to seek out and use the free medical services provided by the Community Health Program. These barriers to care include the lack of money or health insurance, lack of knowledge about resources, mobility, flexibility, fear, stigma and pride, and health legacies. The research participants also identified the seemingly uncaring “treat and street” attitude of some physicians—
what one patient called “assembly line medicine” as a deterrent for seeking out medical care. Each of these barriers were explored through the examples and stories told by the patients and CHP staff members.

In Chapter 5, I move from talking about the barriers to health to exploring how the Community Health Program works to advance an alternative script of health care through disrupting the gender and class meta-narratives that work to stigmatize and delegitimize their patients. These alternative scripts include (re)organizing space and time, blurring the lines between personal and professional through rapport and report talk, shifting and blurring the front and back stage regions, and breaking down the barriers to health care through navigating, advocating, cheerleading, and creating a patient support system.
CHAPTER 5: ADVANCING AN ALTERNATE SCRIPT OF HEALTH CARE

Providing a Community of Care: Breaking Down the Barriers

One of my first observations with the mobile health clinic was the childhood immunization program. Ah ha, I thought. I know something about the people who are bringing their children here for shots. The socioeconomic status shared by the majority of these people, as well as the fear showing in the eyes of their children, resonated deeply within me.

I entered the clinic that first day with considerable trepidation as I did not know what to expect. My hope was that I was not going to witness the immunization process I had endured as a child. I was not sure I could emotionally handle children being subjected to the treatment I had received at the hands of health department personnel when I received my free immunizations. Much to my surprise and delight, the clinic staff recognized the importance of gaining the children’s trust and making them part of the medical intervention and interaction.

One way in which the staff connected with the children in the story above was by approaching the immunization process as a shared and storied experience. Staff members often shared stories from their personal lives with both the parent and the child to make the immunization experience less frightening and stressful for all concerned. By sharing personal stories, the staff blurred the boundaries between personal and professional talk to aid in the treatment of their patients. For example, one of the nurses, Jen, used the analogy of blowing out candles on a birthday cake to help distract her young patients from the fear of receiving their immunizations. During one childhood immunization clinic, Jen was telling her colleague, Linda, about the new stethoscope her husband had
given her the night before as a birthday present. As the next child came into the room for his immunization, Jen employed this personal birthday story again, not because it allowed her to present herself, but because her story could do something for a scene of wider scope (Goffman, 1959).

The next child who came to the clinic had turned four yesterday (sharing a birthday with Jen), and so Jen shifted the conversation from her birthday to the child’s birthday and they talked about the Blue’s Clues cake he had at his party. Jen asked the child if he had blown out the candles on his cake and he said yes. “Can you do that for me again now, except this time blow on your mom’s hair,” asked Jen. “No,” said the child. “It’s not the same.” “Well, you don’t have to blow out if you don’t want to, but it will help you to not feel the sting of the shots as much,” Jen said. Jen often used this analogy of blowing out the candles to help the children focus on something other than the pain of the immunization. (Field notes)

The treatment of the patients during this childhood immunization clinic was not happenstance or a one-clinic occurrence. Throughout the various clinics, CHP staff regularly used stories to create a common bond with patients, to ease the sting of stigma, to honor tradition and culture, to preserve a sense of dignity and pride, and to create a comfortable and nonjudgmental space. Many times this sharing of stories formed a common ground or opened up a reciprocal dialogic thread that helped medical personnel dig deeper into the root cause(s) of illness or health issues. Charon (2006) supported this embodiment of narrative as she implored medical caregivers not to simply rely on their medical expertise, but to also learn to listen to and respect their patients’ narratives about
illness. An element essential to thinking and knowing in clinical medicine, these narratives remain mired in the circumstances of human experience (Montgomery, 2006).

While conducting my research with the Community Health Program, I traveled over 1,700 miles observing the free diabetes, medical, breast and cervical cancer, and healthy adult screenings, the perinatal program, and the childhood immunization clinics. During this time, I regularly witnessed an extraordinary mode of comprehensive and personalized medical care. The standard ethic of care administered to the patients throughout the free medical clinics far exceeded the majority of medical interventions in which I have been personally engaged as a patient. This is not to say that my personal experiences with the traditional biomedical model can speak for everyone as the clinical communication style of all doctors, patients, and settings are not comparable (Sharf, 1993). However, the data collected through field observations and from personal interviews with staff and patients clearly shows evidence that there is something special and unique about how the CHP staff administers medical care. These stories and experiences of extraordinary care will unfold throughout my subsequent conversation in Chapter 5.

In this chapter, I discuss how the Community Health Program advances an alternate script of health care that helps to break down many of the barriers encountered by the patient base they serve. I begin by describing how the clinics (re)organize both physical and personal space to foster a sense of community for medical intervention and how time is (re)organized to counteract and complement the temporal rhythms of mainstream medicine. Next, I describe how staff blurs personal and professional talk as they shift between the frontstage and backstage areas of the clinic. Finally, I describe how
staff disrupt the master narratives of health care as they assume the roles of patient navigators, advocates, and cheerleaders, and as they provide a support system which often extends above and beyond simple medical care.

(Re)organizing Space: Recasting Stories of Illness

The physical space constraints on the mobile vans lead to difficulty in maintaining patients’ privacy scripts and present challenges in maintaining a separation of the frontstage and backstage areas for patient examination and staff consultations (Harter et al., 2008). Although these identified space limitations continue to create challenges, they also create opportunities in which patients and staff can interact closely with one another. In the following section, I examine how the (re)organization of physical and personal space helps break down barriers to health care by disrupting the meta-narratives that privilege status and promote patriarchy and by providing an atmosphere that fosters a sense of community, identification, and consubstantiality among and between the patients and the staff. As Sally, a nurse coordinator, explained, “Patients usually tell me a whole lot of things they don’t usually tell. I think for some people, this is the only chance they ever get to tell their story and to have someone really listen who is not there to judge what they’ve done or to judge their personal situation” (staff interview).

The door to the mobile van opened and a middle-aged woman poked her head inside and asked if she was in the right place for the free medical clinic. Danielle, a CHP nurse, said “You sure are, come on in and have a seat.” Danielle introduced herself to the patient, found out her name, and handed her a clipboard full of paperwork to complete in preparation for her exam by the nurse practitioner. While Kay waited her turn, the three of us and one other patient
conversed about the weather, about gardening, and about the upcoming presidential election. After the nurse practitioner finished examining Kay, I stepped into the exam room to ask her about her experience with today’s care. When I asked Kay how comfortable she felt using the clinic, she told me that she felt much more comfortable here than she ever had at a regular doctor’s office. “I’m glad that there’s only women on here and that made me feel more comfortable during the exam. But, that’s not the only reason why I felt so comfortable. I just got a good vibe when I opened the door—you know how sometimes you can just tell what a place is like when you walk in—that’s how I felt when I opened the door and came inside today” (patient interview).

Denice was surprised by the quality of medical care she received on the mobile van. She had not been sure what to expect when she climbed up the steps and entered the van’s waiting area. She was scared, she was embarrassed that she had to accept free medical care, and she was uncertain whether, as an African American, she would even be welcome. Denice described how she was put at ease immediately when Julie welcomed her at the door with a friendly smile and an invitation to come in and have a seat. She felt so at ease that she soon found herself joining in conversation with the other patients who were waiting. Describing her experience on the van as “fun”, Denice shared the following overall impression:

The environment was so much better than I expected and much different from a doctor’s office (in a good way). No one sat behind a glass window and people didn’t try to avoid eye contact or talking to each other. No one made me feel ashamed for being there, for being down on my luck. I was treated with dignity.
They asked questions and then they listened—they really cared about me and they let me talk. The doctor (nurse practitioner) asked about the scar on my breast and I told her it was from an infection I got after a beating from my ex-husband. I don’t usually tell people that stuff, but I felt good with her. (Patient interview)

In order to understand how the physical space is (re)organized in the mobile clinics, I will provide a mental snapshot of how the allotted spaces are configured, both in the primary-use vehicle and in makeshift public venues. I have also provided actual photographs of the outside and inside of the primary use van below. Although the CHP has two medical vans, one van is most frequently used for the breast and cervical program and the free medical clinics because the lay out of the vehicle is more patient and staff user friendly.

Image 1: Community Health Program Mobile Van
The space configuration in this particular van somewhat resembles a traditional doctor’s office with its waiting area, an intake room, and an examination room. However, this is where the resemblance ends. Upon opening the entry door to the unit, patients step into a 15 feet x 7 feet waiting area that consists of small padded bench seats on either side of the van. Also located within the waiting area is a staff work station with overhead cabinets and drawers that hold patient folders, a copy machine, pamphlets and educational literature, and a variety of medical information and history forms. There is just enough floor space in the middle of the waiting area for one person to walk comfortably between patients who are seated on the bench seats.

Image 2: Patient waiting area and coordinator office space inside mobile van
There are two 7 foot rooms located at opposite ends of the van which are used for patient processing, assessment, and examination. In addition to the examination table, the exam room (pictured below) located to the left of the waiting area houses a handicap lift and a storage cabinet/sink.

Image 3: Examination room on CHP mobile van

The room located on the right side of the waiting area, typically used for patient intake (paperwork review, medical history, and vitals) houses an examination table, storage cabinets and a sink (see photo below). As can easily be seen from the photos and dimensions, patients and staff are closely joined together in this cramped and tightly configured space.
Clinics held in public venues, such as senior centers, churches, and schools, are also confined to very limited space. These venues are principally used for healthy adult screenings because patients do not need a space to undress for examination, and private consultation between the staff is minimal. During a typical clinic, staff set up three cafeteria-style tables in their allotted space down a hallway, in the corner of a sanctuary, or across the front of a lobby. One table is used for patient registration and intake, one is used for patient assessment (for example, taking blood pressures), and one holds equipment (for example, diabetes screening monitors). As on the mobile van, patients and staff have little room for separation or privacy. However, these small spaces also provide
the opportunity to break down barriers as the staff and patients come to know one another on a more personal level.

The concept of (re)organizing space in the mobile clinics takes on a literal and a symbolic significance. The CHP staff incorporates a psychological and social aspect into their health care regiment because “the mind-body approach to medicine is not a dichotomy but a dualism that promotes improved patient care and views the doctor-patient relationship as a complex interaction” (Rakel, 2002, p. v).

Certainly the limited physical space literally necessitates that patients sit in close proximity to one another and to the CHP staff. However, even when the clinic space is filled with patients who do not know one another, the CHP staff has been able to create an environment that provides a space for patients to comfortably share their lived experiences. One vivid example of this sharing of lived experiences occurred at a breast and cervical cancer screening.

Jeanette and Loretta boarded the van together. Even though Jeanette has been divorced from Loretta’s brother for a number of years, the two still regard each other as sisters. They have been coming to the B&C clinic together for at least three years because only Jeanette can drive and because both are uninsured. The clinic was especially busy and the van had only two seats left which Jeanette and Loretta filled. Loretta started talking about how much she hated to have her yearly exam done and the other two patients, Dorothy and Carolyn, added their thoughts about the procedure as well. Loretta then shared that she and Jeanette always go out to eat and then go shopping at Wal-Mart after their pap and mammograms. Carol, the nurse practitioner who had been listening to the
conversation, asked Loretta how many men she knew who would get a prostrate exam and then go out to eat with their buddies. We all shared a good laugh when we agreed that not one man would even think about it!

Jeanette began talking openly about being diagnosed with vaginal dermatitis and how she had been doctoring for two years and had used every kind of antibiotic and cream the doctors could think of. Carolyn inquired about which doctors she had seen and what kind of medicine she had used. Carol asked if she had brought the medicine with her and Jeanette fished around in her purse and pulled out the tube and handed it to Carol. She also made sure to let us all know that the dermatitis wasn’t caused by something she had done sexually; it was just one of those “female” things. (Field notes)

Sometimes the clinics serve as a reconnecting point for community members or friends. Carol, a nurse practitioner, shared the following story about a group of old classmates who unexpectedly met up on the same mobile clinic.

Yesterday, there were some ladies who were classmates and they hadn’t seen each other in five years since their last class reunion. So, they started talking about their grandchildren and about so and so who was in the hospital. Julie told one of the patients she could go into the exam room now, and I said “I know you’re ready to start the intake, but she’s got to catch up with her friend here.” Then somebody said, “why don’t you give her your phone number and she can call and you guys can go out for breakfast.” Somebody else said, “yeah, that’s a good idea—Mary give me your phone number.” They were yelling through the exam room door—it was kind of cute. A lot of women come on and just by accident see
people they know or that they used to work with or that were old classmates. We see a lot of people reconnect. (Staff interview)

To disrupt the barriers of mobility and flexibility in receiving health care, the mobile clinics often set up in small towns throughout their service area. This practice also helps break down the barriers of stigma and pride by sending a message that the people in these areas are important enough to make an effort to bring care to their doorstep. For example, the mobile clinic has held several free medical and cancer screening clinics in a small, rural, economically depressed community. The van opens up shop in front of the local senior center, which is housed in one of the nicest run-down buildings in town.

Marie, a CHP nurse, told me that trust was hard to establish in this town, and as a result, the first few clinics had very few patients. However, as part of her church’s outreach program, she started coming to the senior center once a week to take blood pressures. Through this interaction, she was able to establish trust and to eventually convince people to give the mobile clinic a try. The day I observed here, the clinic was heavily scheduled with patients all day. The last patient of the morning invited us all to come to the senior center with her for lunch.

*Although we had all packed our lunches for the day, we decided to accept the graciously offered invitation. Our decision carried a duel purpose—we were fearful that turning down the invitation would be seen as rude and we were hopeful to build relationships through the breaking of bread. Shortly after noon the five of us (nurse practitioner, AmeriCorps volunteer, nurse practitioner student, nurse, and me) entered the senior center where we were warmly welcomed and invited to find a seat at one of the available cafeteria tables. The*
minister who coordinates these weekly luncheons asked those gathered to keep Jimmy in mind as he was having his voice box and tongue removed due to cancer that day. He then said a brief prayer before beginning the meal. Once the blessing had been offered, he introduced the five of us, made a big deal about our being there, and invited us to go first since we were honored guests. We went through the line and filled up our plates and returned to our table to find five older men sitting across from us. The one directly across from me asked if we were with the medical van and Annie told him that we were. He held out his arm, which had a long narrow scar from his elbow to his wrist, and told us the doctors had taken a vein out of his arm, as well as out of his leg, to do heart surgery. Annie told him that she worked for cardiologists in Lancaster while learning to be a nurse practitioner and asked where he had the surgery done and who his doctor was. They talked about his surgery for a bit more and then the man turned and introduced the older man sitting next to him. “This here is Trevor. You ought to see the wood carvings he does with a chain saw. Man, he does some good stuff.” I asked Trevor what he carved and he said totem poles and bears. Jason, vein man as I thought of him, interjected that Trevor also made arrows out of roofing slate. I then asked Trevor to tell me about how he did the carvings on slate, if he sold his carvings, and where he sold them.

The conversation finally turned more personal and Trevor asked where I was from and I told him Athens. “Is that where you lived all your life?” When I told him that I had grown up in Jackson, he wanted to know where I lived in Jackson. I laughed and replied that I had actually grown up in Ray which is about
30 minutes from Jackson. “I know where Ray is” he said. “Do you know where the general store used to be—there by the railroad tracks?” I laughed again and told Trevor that this story was getting complicated because while Ray was our mailing address, I had never actually been to Ray. When I told him I had grown up in a hollow without running water or indoor plumbing, he laughed and asked me if I was a hillbilly. I told him that I absolutely was a hillbilly—this pleased him greatly and he told me that he now knew why he liked me so much.

After lunch we thanked everyone for inviting us and left to go for a short walk before the afternoon appointments began. As we walked, we shared some of the stories we had heard during lunch when talking with the various seniors. All five of us agreed that we had a delightful time visiting with the people and that we had made the right decision by sharing lunch with them. We had joined medicine with the spirit of the community, and I optimistically hope our people investment will be returned through a larger patient count in subsequent clinics. Later that afternoon, Trevor showed up at the mobile clinic door with a piece of slate he had painted and insisted that I take it as a gift. I thanked him, gave him a hug, and told him I was honored he would share his beautiful work with me. After Trevor left, nurse practitioner Carol remarked that this type of bridge-building interaction made her feel hopeful. “It’s obvious that we made people feel comfortable here today just by letting them get to know us and realize that we are people just like them. Just because we are more educated and we are medical personnel doesn’t mean we don’t come from the same place” (field notes).
Metaphorically, patients are given the space they need during the intake and examination to talk about not only their health issues, but underlying factors that might be contributing to their illness(es) and/or to the illness(es) of family and friends. Judy, a patient in a B&C clinic, found that the CHP staff provided a comfortable, caring, and competent atmosphere in which to tell her story: “They not only took good care of me, they allowed me space to talk about personal issues. I told Carol about a medical problem my sister was having and Carol gave me information on the free clinics and encouraged me to get my sister an appointment” (patient interview).

In other instances, the clinics serve as a venue for social networking while also providing an educational component. During a healthy adult program (scheduled to coincide with a food pantry distribution) in the lobby of a small community church, three sisters came over to the screening area to have their glucose, blood pressure, and cholesterol tested. While the three were taking turns getting screened and learning what their numbers meant, three or four other friends who had received their food allotments came over to see what was going on.

As I watched the patients and their friends exchanging personal medical information like friends exchange gossip in the aisle at the local Kroger, I could not help but think that HIPPA would have a field day here with the lack of patient privacy. Everyone was asking everyone else what their numbers were and leaning over the screening tables to observe the testing process. Gina, who was doing patient intake, remarked to me that you just didn’t see this kind of community in larger cities—this was Appalachia at its finest. She also thought this reaction was in part due to the small, comfortable setting. (Field notes)
During my interview with Dr. Roberts, an osteopathic physician who volunteers his time at the free clinics, I asked him how he approached the task of taking a patient’s medical history to ensure they were given space to foster an environment of ethnographic exchange. Dr. Roberts responded that everyone is a mini-ethnographer and everyone has a story to tell and “no matter where you come from, how much money you have, or what your ethnicity is—people are people and families are families” (staff interview). In order to elicit these mini-ethnographies from his patients, Dr. Roberts employs the BATHE technique as described in Stuart and Lieberman’s (2002) book, *The Fifteen Minute Hour*. Dr. Roberts explained that using the BATHE technique allows physicians to gather a significant amount of history (both personal and medical) in a shortened period of time. BATHE allows physicians, often rushed to fulfill patient quotas, the ability to extract and supplement standardized medical records that “reflect a biomedical assessment of the patient that relies on claims of objective data and systematic objective evaluation” while noting “little about how patients feel about their diagnosis, how they are coping, or what their illness means to them” (Ellingson, 2005, p. 67).

As Dr. Roberts further explained, the letters in BATHE pertain to a specific set of questions that patients should be asked during the history taking portion of the exam to help draw out their stories and health-related information. He grabbed my note pad and proceeded to draw out the following diagram while explaining what information each letter could elicit from a patient:

- **B** is Background: “What’s going on in your life?”
- **A** is Affect: “How do you feel (about ……)?”
- **T** is Troubles: “What troubles you the most (about …..)?”
**H** is Handling: “How are you handling (it)?”

**E** is Empathy: “It must be very difficult.”

After explaining each of the steps in BATHE, Dr. Roberts then turned the paper over to the other side and said we would look at how the traditional biomedical process worked. He then drew out the protocol that physicians use with patients when following the traditional biomedical model.

**CC** is chief complaint about why they are seeking medical intervention

**HCC** is the history of the chief complaint (When did this begin?)

**PMH** is the past medical history (includes birth history, family history, surgeries, hospitalizations, daily habits (smoking, recreational drug use, coffee, juice, water, sleep, diet, etc.)

**ROS** is the review of systems (includes history of nausea, vomiting, diarrhea; urination problems, etc.)

Although Dr. Roberts firmly believes this traditional protocol is very important to follow to document a patient’s medical history, he also believes that the BATHE technique is crucial in helping to identify the deeper root causes of a patient’s illness. Similarly, Montgomery (2006) suggested that the “Diagnosis and treatment choice are not simply matters of logic or a patient preference exercised in the moment but a more contextual consideration intertwined with history, identity, culture, and meaning of an individuals’ life” (p. 49).

As Dr. Roberts discussed the differences between the BATHE process and the traditional biomedical method in learning a patient’s history, I realized the BATHE technique helped to disrupt the traditional scripted and performed meta-narratives of
By delving into the antenarrative (Boje, 2001), the BATHE technique facilitates uncovering the patients’ lived experiences that might potentially be contributing to their current health and illness issues. An antenarrative in essence acts as a set of schematics for medical personnel as they gather the fragmented, nonlinear, and collective stories that are constructed within the multiple registers of their patients’ bodies. The resulting pre-stories gleaned from the antenarratives help to answer the question, “what is going on here?” (Boje, 2001, p. 3).

When working with parents who have children with behavioral issues, Sally naturally seems to fall into using a technique that closely mirrors the BATHE approach. While observing Sally’s interaction with Mary, the mother of a child suspected of having a behavioral disorder, I witnessed a subtle but effective shift in how information was gathered in order to collect the pieces of the puzzle.

Sensing her discomfort with talking about her son’s behavioral issues, Sally deviated from the standard list of questions and began to ask open ended questions to give Mary space to start her story wherever she needed to and to take the interview in any direction she needed it to go. Sally’s questions became invitations to narrate, “Tell me what’s happening with Barry.” “What’s going on with him?” “How do you feel when he says or does that?” “And how does dad react when that happens?” There was a noticeable easing of the tension in Mary’s body as she was invited to tell her story in her own way and she began to share not only the medically-related symptoms of her son, but also the personal stories of her husband’s drug abuse that she felt contributed to the behavioral problems.

(Field notes)
After Mary left, I asked Sally to explain why she felt she was able to connect with her patients so well. “I think what makes me pretty good at my job is that I can talk to people coming from the same place I’ve come from and they don’t have to protect themselves any more. They can let some of that guard down, and we can talk honestly about things that maybe they’ve never talked about before” (staff interview).

The approach to healthcare promoted by the mobile clinics also helps to foster a consciousness of identification and consubstantiality (Burke, 1969). By creating a discursive space that allows the use of narratives to tell of the struggles encountered in the patient’s every day lives, a common bond is forged in a common space that promotes communication with others within that space. I argue that this creation of identification and consubstantiality is not limited to the patients alone but, instead, is multifaceted, circular, and entwining as it also encompasses the caregivers and others involved with caring for patients throughout the Community Health Programs.

A sense of identification refers to the perception of oneness with or belonging to a particular human group (Russo, 1998), it facilitates communication, understanding, and a sense of common purpose, and it provides a feeling of connection or consubstantiality (shared substance) between two otherwise separate individuals (Gossett, 2002). A product or state of identification that leads an individual to see things from the “perspective” of a target (Cheney, 1983), consubstantiality represents an area of “overlap” either real or perceived between two individuals or between an individual and a group and is a basis for common motives and for “acting together” (Burke, 1969).

Carole, a nurse practitioner who did not grow up in Appalachia, was surprised at the sense of community and identification the mobile clinics and their staff engender with
patients. She shared the following encounter she and her husband had with a former clinic patient.

In the first two weeks of working this job, my husband and I were in the Pomeroy area and we stopped at McDonalds. The lady behind the counter said “you’re that lady from the van, aren’t you?” I recognized her then. My husband thought that was pretty funny, that you’re far away from home, far away from Athens, and someone recognizes you and treats you like an old friend. That’s a good feeling to know that you’re touching people’s lives in these communities. (Staff interview)

The Community Health Program staff found that they could relate to and connect to patients on a deeper level if they were open to sharing personal stories about their families, their hobbies and interests, and their personal experiences with health-related issues such as being a breast cancer survivor or being a former smoker. Karla, an AmeriCorps volunteer, recalled a story when nurse Danielle was able to use her church as a common bond to encourage a patient to seek more intensive medical treatment.

Danielle had this woman who was real apprehensive about seeing a doctor. When she found out they both went to church, that helped them connect and really develop a caring relationship. I think that maybe this is a way for people to form connections that are based on values and individual circumstances. (Staff interview)

Danielle’s willingness to talk about her faith and church attendance provided the overlap and basis for a common motive that led this patient to seek additionally needed medical care. When I asked Danielle to share a story of a time when she felt she had been
able to make a critical difference in a patient’s life, she immediately mentioned the same story that had resonated so deeply with Karla.

I wouldn’t have found that out (cancerous lesion between breasts) had I not talked to this patient about church and had we not gotten real comfortable with one another. She was there for blood pressure only and had I not been able to establish a rapport with her and share some of my experiences with her, the cancer might not have been found before it was too late for any treatment. She wasn’t going to show the doctor—she was there for her blood pressure and nothing else. When she opened her blouse and showed me her breasts, I was stunned that she had been living with this sore and had not told anyone. She was carrying this burden all alone. She’s had surgery and is taking chemo and radiation now. I call her every couple weeks to see how she’s doing—we still don’t know if we caught the cancer in time but it’s important to me to let her know I’m still here and I still care about her. (Staff interview)

Sally was also quick to stress how important establishing common ground is with her patients: “Sometimes I think if they’ve never talked about things before, they think that they are the only people this has ever happened to or that are feeling that way. It helps if I can say not only has it happened to you, it’s happened to me and it’s happened to a whole bunch of people out there. It’s not just a common bond, it’s helping the patient understand that they’re not crazy or weird or alone” (staff interview). Monica, one of Sally’s patients, was relieved to hear that someone understood exactly where she was coming from: “Sally was sympathetic with what we were going through and because she has a son with behavioral issues—I think that helped to hear my son wasn’t odd or
unusual. Just having something in common—she could easily empathize with us. She has been there too” (patient interview).

Along with the barrier of fear, another closely related and underlying barrier to seeking medical care is the issue of trust. Rakel (2002) recognized the importance of establishing trust with patients and cautioned that “patients must believe that we value their comments and opinions before they will trust us with information of a personal nature” (p. v). This caution is especially meaningful when working within the boundaries of a closed Appalachian culture where trusting outsiders does not come easily to its people.

Molly, a nurse coordinator with the perinatal program, understands that truly listening to her patients and respecting their traditions and values are essential ingredients in developing the trust needed to facilitate critically important prenatal care. As she explained, “I think it’s important to find out what the bigger issues are and to do that I’ve got to establish a trusting relationship so they will share those issues. I think whatever is going on in their past or present; I think it’s important that we listen” (staff interview). During a staff meeting at the OB/GYN office, one of the physician’s nurses reiterated how important this trust is to the patients under Molly’s care: “Patients don’t like it when other staff members fill in when Molly is on vacation. Once Molly earns a patient’s trust, they don’t want to deal with someone they don’t know and who doesn’t know them” (field notes).

As I discovered throughout my many months of observation, asking questions is an important method of gathering data. However, I also discovered that sometimes just sitting back and quietly observing worked equally well. There were many times during
my observations when I sat in the waiting area instead of going into the exam rooms so that I could hear what the patients talked about with each other and the CHP staff members. Often I engaged the patients in general conversation and, on more than one occasion, became their liaison with the CHP staff. For example, a couple of patients told me that they would prefer to have Carol examine them instead of Dr. Roberts because of previous unpleasant encounters with male doctors. There were also instances when patients would confide to me that they were afraid of the exam procedure because of past experiences, or that their spouse had just passed away, or they had just gotten a divorce, or they were ashamed to be there but had no other treatment options. In each instance, I would make sure that the nursing staff or the nurse practitioner knew what they were dealing with before they began talking one-on-one with the patient. Julie, a nurse coordinator, told me that this “inside” information helped them provide better care for the patients.

During one of our conversations, Julie asked me what else I was learning from listening to the patients’ stories as they sat in the waiting area. I told her that I was beginning to understand that the patients needed a space to talk, not just about their illnesses and health but, also, about their lived experiences and how those experiences were impacting, or have impacted, their lives. Perhaps, I told Julie, the stories are not necessarily in the telling of health and healing, but in the lived experiences themselves that create the need to talk about health and healing. Or, as Danielle explained during a staff interview, “People need to know that they matter and that they matter to somebody” (staff interview). Montgomery (2006) talked about the important role narrative plays in a patient’s diagnosis and treatment saying, “. . . narrative perception and construction
requires the capacity to understand the patient and recast his or her story of illness into a medical narrative that can be matched with the diagnostic taxonomy and lead to appropriate treatment” (p. 50).

These are but a few of the many examples and stories that I could share from my observations and interviews that illustrate the important role (re)organizing space plays in creating common bonds and establishing a comfortable and inviting environment for patient care. However, simply creating an environment where patients feel comfortable sharing their lived experiences and their stories of health and illness is only part of the equation used to provide an alternative script of health care. The next ingredient needed in this recipe is the (re)organizing of time to allow these stories to be heard.

(Re)organizing Time: Transforming Temporal Rhythms

“The basic dimension of human existence is temporality, and narrative transforms the mere passing away of time into a meaningful unity, the self” (Polkinghorne, 1988, p. 119).

Montgomery (2006) acknowledged that the time physicians spend with patients is critical for constructing “a recognizable clinical account of the patient’s illness” and for them to “transform details of the patient’s illness narrative into clues that will match one disease plot better than others and clinch the diagnosis” (p. 61). In a traditional medicalized model, patients routinely spend considerable time sitting in a room waiting for their turn to see a physician. The patient is rewarded for this long wait by getting to spend approximately 10-15 minutes (if the patient load is light) with their physician. And, more often than not, the physician will only treat one chief complaint per visit. This “treat
and street” mentality allows little time for patients to share much more than the location of a pain or the most pervasive symptoms they have been experiencing.

The CHP staff realizes that “between the activity of narrating a story and the temporal character of human experience there exists a correlation that is not merely accidental but that represents a transcultural form of necessity” (Ricoeur, 1984b, p. 52). Therefore, to counteract the temporal rhythms of mainstream medicine, the CHP clinics are scheduled to provide shorter waiting times and to allow for longer patient-physician interaction in a slower paced, more relaxed environment. Granted, the CHP staff does not have patient quotas to fill or a specific number of billing hours needed to produce an income stream most practices need to stay in business. This lack of constant financial dependency actually allows staff to practice a more patient-centered medicine by spending the time needed to elicit the myriad factors that contribute to their illness(es).

However, as is evidenced by my conversation with nurse practitioner Melinda, the staff is aware of the tenuous position the clinic is in because of shifting and eroding funding.

After a morning of observing her examine patients, I remarked to Melinda how impressed I was with the amount of time she devoted to each patient and the thoroughness of the educational component and actual exam. Melinda replied that she likes the way the mobile clinics schedule patients because it allows her time to spend with each patient, a luxury that most physicians do not have because they have to see a certain quantity of patients each day to pay the bills. Melinda said that one of the CHP clerical staff asked her how many patients she had seen at a recent clinic and she replied, “I don’t know how many I saw. I don’t count
patients. I’m there to give them the best medical care and education that I can.”

The clerical staff replied back, “I know you don’t count patients, but we have to be concerned with how many we see because of our funding. We have to be able to justify our existence.” Melinda said that made her angry that the people in charge were more interested in quantity than quality. (Field notes)

Charon (2006) stressed the importance of (re)organizing the time devoted to patient care claiming that medicine becomes transformed when it is practiced with a respect for time and timeliness. As she further explained, time is a necessary axis in diagnosis, in prevention, in palliation, or in attempting cures. Taking the time to listen, the time to care, and the time to recognize each individual patient’s story of health and healing is an irreplaceable ingredient in the healing relationship.

Danielle, a CHP nurse, believes the mobile clinics provide a unique environment, a unique sense of space, and an allotment of time for each patient that is not typically found in traditional biomedical care. Before accepting a position with the CHP, Danielle worked for several years as a nurse for a group of doctors in a primary care facility. She bases the following viewpoint on the differences she has witnessed between her former position and her current position working on the mobile vans.

Sometimes we’re the only place patients get to tell what they want to tell someone who will listen to them. I think it’s important to their care. They are getting the best nursing care and the best physician or nurse practitioner care because they have our undivided attention. We don’t have phones ringing; we don’t have patients walking in and out wanting certain things; and we don’t have a lot of staff needing things. I feel like we have a lot of time to do one-on-one. I think they get
better care than you and I get when we go to our physician’s office and our insurance pays. (Staff interview)

Rhonda, a breast and cervical cancer screening patient, did not know what to expect when she climbed on board the van for the first time. Although she was nervous, she explained that she was immediately put at ease by the friendly staff and they seemed to have time to talk to her and relate to her situation.

The lady I talked to just in general made me feel more comfortable—she really did make me feel more at ease. We ended up talking about everything—kids, the beach, gardening—just really talking. The other patients and the staff—they just sat and socialized until it was time for my exam. Even the physician who examined me, she just brought it down to “How does this affect what you do?” “How does this affect your life?” She just put in more personal care and time than you get at a doctor’s office. (Patient interview)

During our personal interview, Dr. Roberts spoke about the importance of combining the psychological and social aspects of health care along with the biological, clinical or scientific model. Believing that there is a difference between “taking a patient’s history” and “hearing the patient’s story” (Frank, 1995), Dr. Roberts spends as much time talking with patients as is needed to obtain a comprehensive overview of their medical and personal stories. CHP nurse Danielle believes that Dr. Roberts embodies a narrative mindset when talking with patients. When I asked Danielle to explain why she felt Dr. Roberts provided a different type of care to patients, she responded:

Dr. Roberts never gets in a hurry when he’s with a patient. He may disappear with a patient for an hour if that patient wants to talk to him. He asks them questions
about everything and has a conversation with them. You just never know what you’re going to hear that’s going to help you understand that patient better and enable you to treat them. The mobile clinic is the ideal setting for Dr. Roberts because we have the time for him to spend with each patient. Dr. Roberts’ people and interpersonal skills are amazing—he makes time to listen. He understands that making time to listen leads to making better decisions in regard to diagnosis, treatment, care, and the subsequent healing of our patients. (Field notes)

The mobile clinic patients are quite vocal about how much they appreciate an environment that balances less time in the waiting room with more face-to-face contact with medical personnel. Carol, a nurse practitioner, shared the following feedback she has received from her patients:

What I hear a lot of from the women who come is that they like the staff and they like that they don’t have to wait a long time. I’ve heard comments that women go to their family doctors sometimes and have to wait an hour or more for their appointment. I’ve also been told that women like the fact that they can really talk to us and that we listen. We don’t rush them out of the exam room so we can get to the next patient. A lot of women have brought their friends to us because they’ve had positive experiences here. (Field notes)

Judy, a free medical clinic patient, had not sought medical treatment for some time because of her financial situation and because the environment always seemed so cold and rushed. She enjoyed the laid back atmosphere in the mobile clinic and the staff took their time with her and did not try to hurry her out the door: “That means a lot, especially when you are hesitant to seek treatment in the first place. It is a good feeling to
know that they (medical staff) are not looking at you as just a body but as a human
being.” (Patient interview)

One of Carol’s breast and cervical cancer screening patients, Wendy, was
surprised by and impressed with the treatment she received during her exam. She
described the interaction as follows:

Carol indicated her interest in talking to me by asking point-blank questions and
then she let me finish the sentences. Some doctors just keep on asking questions
before you even finish the sentence about the previous question. Carol would ask
more specific questions from the answers I gave and she listened to what I had to
say. It’s very important to have someone listen to you ‘cause if you don’t listen,
how you gonna fix it? Like my mom always said, you don’t lie to your doctor.
Well, you don’t lie to your doctor but then he needs to listen. How they gonna
treat what may really be causing your problem? They’ve got to learn to listen to
the whole story and not just rush you in and push you out. And they do that
here—they really take as much time as you need to listen. (Patient interview)

The last story I will share comes from Betsy, a first time patient in a rural free
medical clinic. When Betsy entered the clinic, I could not help but notice her ragged
clothing, her long stringy hair, and her sunken mouth absent of teeth. As she sat waiting
for Danielle to call her back into an exam room, I told her that she looked very familiar to
me and I was sure I had met her before. She revealed that she used to work at a fast food
restaurant in town and I remembered seeing her there. She told me that she was ashamed
to be using the free clinic but had no where else to turn due to her financial situation. I
assured her that she had no reason to be ashamed and that we were pleased that she came
to us for treatment. When Carol had finished with Betsy’s exam an hour later, she told me that Betsy would be glad to talk to me about my research project. Betsy gave me a big grin as I entered the exam room and told me that she really liked Carol and Danielle and they had done a good job. When I asked whether she found any difference between the care she received today and the care she received in a traditional doctor’s office, she responded as follows:

Oh my, yes. When talking with other doctors, it seems they are always busy and in a hurry. I don’t tell them all my problems because I don’t feel like they have time to listen. I think having a clinic run by women is a welcome change, and them talking and asking personal questions makes a difference when you’re scared and unsure. Maybe they take more time ‘cause they’ve gone through some of the same things as us. I mean, somebody taking time to talk to me—just being treated like a human makes a difference. (Patient interview)

The (re)organization of space and time is one way the CHP staff provide an alternative script of health care to their patients. They not only take a patient’s medical history, they listen to the patient’s narratives of health and illness to determine what led them to seek medical intervention. The staff is able to make connections with their patients through establishing common bonds, through identifying with their lived experiences, and through providing an exceptional ethic of care. In the following section I will continue to examine ways in which staff work to establish deep and trusting connections with the patients—the blurring of personal and professional boundaries.
Blurring Personal and Professional: Mixing Rapport Talk and Report Talk

Dr. Deborah Tannen (1990) investigated the differences in the public and private speaking styles of men and women. Her research indicated that women feel more comfortable doing “private” speaking while men feel more comfortable doing “public” speaking. The terms Tannen coined to reflect these communication style differences were rapport-talk for women and report-talk for men. For women, she suggested, the language of conversation is primarily a language of rapport: “a way of establishing connections and negotiating relationships” with an emphasis placed on displaying similarities and matching experiences (p. 77). Women, for the most part, enjoy talking with people they feel close to and comfortable with in smaller settings. For men, conversation is “primarily a means to preserve independence and negotiate and maintain status in a hierarchical social order” (p. 77). To achieve this status quo, men exhibit their knowledge and skill and hold center stage through verbal performance such as story-telling, telling jokes, or sharing information. Men, for the most part, use talk as a way to gain and keep attention and they are more comfortable talking in larger groups made up of people they do not know well.

Although I was not comparing the situation in the context of male/female conversational styles, I could not help but think that the very essence of Tannen’s rapport-talk (sharing personal information) and report-talk (discussing medical issues and treatment) aptly described the straddling and blurring of these conversational lines. Perhaps the rapport-talk came more easily because the majority of patients and staff are women and the phenomena would not occur if the demographics were different. This idea is certainly fodder for an additional research project at another time. What I do know,
however, is that this blurring of boundaries resulted in putting patients at ease, helped establish common bonds, fostered a sense of community, and helped build connections and trust.

In her study of negotiating frontstage and backstage teamwork, Ellingson (2005) determined that communication is intricately interwoven between the two stages and that the boundaries are fluid and permeable. The limited space on board the mobile van naturally lends itself to adapting this fluid, interwoven communication as staff and patients move back and forth between the frontstage (waiting room) and the backstage (intake and exam room). During my field observations, I was struck by the constant blurring of boundaries between personal (rapport) and professional (report) in the front and backstage areas of the clinics as CHP staff shared their personal and family stories of health and healing with patients in the waiting areas and during the medical examinations.

For example, Janie and Sally moved from frontstage to backstage in their interactions often talking about dosages and patients interspersed with personal stories, joking, and informational exchanges about work, the fair, etc. Sometimes this personal exchange started in the frontstage area and continued while patients were in the backstage areas of the clinic. There was no clear delineation drawn between professional talk and personal talk; patients would more often than not join in to share stories of their own or contribute to the conversational exchanges. (Field notes)

One example of sharing personal medical narratives with patients came from Julie, a nurse with the breast and cervical cancer program. Julie sometimes shares with
her patients that she is a breast cancer survivor. When I asked Julie why she chose to share such intimate details with strangers she replied:

Sometimes I do share my personal story of breast cancer, it depends on the case. If I see someone hesitant about getting their mammogram I do, and I’ve swayed them to get their mammograms before. Because I’ve been through it I can say here’s a perfect example because I had no family history of breast cancer, and I had been getting routine mammograms, and I had no breast lump, and wham, one year they found it on a mammogram, and I was 48. I’m the perfect example. I tell that to women who are hesitant about getting their mammograms, and I can usually sway them. I think it helps if patients know you’ve gone through a similar situation because they tend to trust what you’re telling them. I think it also helps staff connect with that person on the other side of the exam table. Patients feel more comfortable when they realize that their doctor or nurse is human too and that they are speaking from personal experience. (Staff interview).

Danielle, a nurse with the free medical clinics, frequently shares her personal life experiences with patients especially when she believes it will help them resolve an issue in their own lives or if she feels they need to know someone understands where they are coming from. When I asked Danielle to share a story of using this approach with a patient she recalled the following encounter.

I’m thinking about a young lady who came in who was actually the same age as my son. After hearing about some of the issues she was facing, I said there must be something about you and this age group because I have a son that’s going through the same things. He’s not interested in this, but he’s interested in that and
she said “exactly!” So I try to share. I think every patient who leaves my area knows something about me and my life and how it pertains to what’s going on in their lives. (Staff interview)

Sally, a nurse coordinator, is quick to let her patients know that she has walked in their shoes as she believes this sharing opens the channel for more honest communication, helps build trust, and helps break down the feelings of stigma and shame many carry with them from being referred to her for medical evaluation and intervention. As she explained:

I’ve shared very personal trials in my life, or I say “I understand that” or “that’s my history, too,” so that patients know it’s not so shameful. It helps that I can talk about what I went through and how it took time and hard work to get things turned around. They need to know that I didn’t feel so damaged that I didn’t do some healing from getting help. In order to help with the medical and behavioral issues, I’ve got to get them to tell me what’s really going on. Once they feel comfortable enough to give me the whole picture I can start talking with them about treatment and intervention options. I think what makes me pretty good at my job is that I can talk to people coming from the same place I’ve come from and they don’t have to protect themselves any more. They can let some of that guard down and we can talk honestly about things that maybe they’ve never talked about before. (Staff interview)

Monica, one of Sally’s patients, said that she was very impressed with how Sally seemed to truly care and how willing she was to put herself out there to illustrate a point. “I mean
she even told stories about her own experiences and stuff. So I felt that she was very easy
to trust and to take her recommendation and feel sure of it” (patient interview).

Although a bit more reticent about sharing too much personal information, Carol
believes that doctor/patient communication can be enhanced through the blurring of
personal and private. When I asked her to explain when she would share personal details
with patients, Carol responded:

Without getting into a lot of detail, I think sometimes it’s nice, in a limited way,
to tell patients that “Yeah, I’ve had that happen to me or one of my kids or my
father or my mother.” I know you’re not supposed to do that too much, but
sometimes I think it’s helpful to use stories without revealing too much about
yourself or your own family. I think patients can relate to things like that. (Staff
interview)

Judy, one of Carol’s patients, revealed how Carol’s use of personal stories helped
her to understand the treatment or medical issues more clearly. “She never gave the
names of anyone, but she’d say I’ve been through this with my family and this is what
they went through and then I would better understand what she was talking about”
(patient interview). Another patient, Wendy, also remembered how Carol’s stories
brought a different prospective to the medical care she received. “Carol—when we were
in there and we were talking about arthritis and things, she was talking about her family
and how it affected her dad and she got more on a personal level. That made me realize
that she wasn’t talking about something just as a doctor, she was talking about something
she had experienced first hand—something she personally knew about” (patient
interview).
Often the CHP staff blurred their professional and personal lives outside the walls of the clinic to help their patients. One of the best stories I gathered to illustrate this extraordinary mode of caring was sparked by my discussion of a recent vacation with staff while we were waiting for patients to arrive.

I was talking with the free clinic staff about the photos I took of the Cliffs of Mohr during my Ireland vacation. The conversation reminded Danielle of the experience she encountered the week before when dropping film at a local one-hour processing center. She thought the clerk at the center looked familiar and she asked him if they had met. He in turn asked her if she was a nurse on the mobile clinic and then she remembered that he had been a patient a couple weeks before. They talked for a few more minutes and then she went shopping while waiting for her film to process. When she went back to pick up her pictures, the clerk looked ill and was sweating profusely. She asked him what was wrong and he told her that his sugar level was probably sky high. Danielle told him to sit down and she would go get a cool cloth for his head. He replied that he could not do that because he would get into trouble and that he only had 20 minutes left on his shift. Danielle stayed with him until he got off from work and then walked him to his car. She offered to either call his wife or to take him home. He told her he was feeling better now and would be able to get himself home. She told him she wanted to see him at the next diabetes clinic and he did follow up by coming in for an exam. Danielle said it was a good thing that he showed up at a clinic because she would have hunted him down to make sure he received the care he needed. (Field notes)
Danielle’s story is only one illustration of how CHP staff continually work outside the boundaries of what is considered traditional biomedical care. As I re-analyzed my field notes and re-read my interview transcripts, a pattern of extraordinary care emerged that often took the CHP staff outside the boundaries of the physical clinic walls. Some of the examples in the following section illustrate how the “doctoring” or “healing” administered by CHP staff often extends far beyond the professional realm of medical care. In other cases, the stories depict how staff members push the boundaries of rules and regulations to assure their patients are not harmed by organizational scripts. The four categories of care discussed below are: navigators, advocates, cheerleaders, and social support systems.

Navigators. The funding for the free medical services comes from a number of sources including local foundations, grants, and state government. As a result, many of the programs are contingent upon renewed funding and operate one fiscal year at a time. Often, the medical staff has to navigate around the funding obstacles to provide continued and consistent care. For example, one of the clinic staff shared the following story during a breast and cervical cancer screening clinic.

We were lucky this year that our Susan G. Komen grant wasn’t cut off during the summer. There have been times when I’ve had to tell women that they would have to wait two or three months to be screened. If someone has a problem, three months is a long time to go without treatment—it could mean the difference between life and death. I also have to be careful that no one gets caught between funding periods. For instance, if we refer them for a mammogram and they don’t
get scheduled before the funding cut, the patient may either be denied treatment or
she may be charged personally for the test. (Field notes)

In other instances, the CHP staff must navigate the numerous barriers to health
care in order to get patients the treatment they need and deserve. Gina (AmeriCorps staff)
believes that the services offered by CHP go far deeper than simply providing medical
care. Indeed, they simultaneously attack and navigate a number of health care barriers
including stigma, lack of money, lack of knowledge about resources, and fear (both of the
treatment and of the system in general). Gina offered this insight into how the process is
enacted:

People in poverty feel like they’re worthless, especially to people in middle and
upper classes which is sad. Many of these people don’t really think about their
health unless it’s an emergency because they run into dead-end walls all the time
and frustrating processes if they even do want to get care. We get on the phone
with them, make contact with them, get their appointments scheduled, and have
them come in, give them the attention and care just like they were everyone
else—which is like it should be because they are just another person. I think most
people are really surprised. I think a lot of people come into the clinic really
closed up, really shut off in terms of talking and communicating and by the time
they leave after having been seen by our nurse practitioner and been given all
their forms to carry out their referral work—they’re different people—like
they’ve let down their shields because they see that we’re not going to be the
people that put them down and make them feel like they’re not on our level.
We’re branching out and I think it’s the fact that we do give such quality care and

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the fact that people are so surprised by it—that’s what makes it so successful—and the fact that we can give them the care they need is what’s rewarding and makes them feel valued. (Staff interview)

Sometimes the CHP staff find themselves helping patients navigate the medical maze by recommending more affordable over-the-counter remedies for illnesses or symptoms that are not life threatening. On one particular clinic, the recommendation for Wal-Mart came up several times throughout the day as patients needed toe fungus medication, calcium supplements, herbs, etc. Melinda, the nurse practitioner, apologized a couple of times to me for sounding like a Wal-Mart ad. However, as she later explained, “these women can’t afford to buy expensive prescriptions or over the counter medicines. If Wal-Mart is the best deal for them, then I’m going to recommend Wal-Mart” (field notes).

As the three examples above illustrate, the CHP staff try to help their patients navigate the often murky and complicated waters of health care. This navigation can include making patients feel comfortable and welcome, helping them complete complicated forms, making referral calls and appointments, or being ever mindful to recommend cheaper alternatives for obtaining medication for minor and non-life threatening illness. In the next section, I discuss how CHP staff serves as patient advocates.

Advocates. Danielle is not the only CHP staff member who carries her work outside the boundaries of the physical walls of the clinic. Although the staff realizes that they often walk a thin line between caring and caring too much, they become so invested in the lives of their patients that they find great difficulty in severing their professional
relationships. In the narrative below Sally describes how her role as caregiver collided with her role as an advocate:

I have this mom that I’ve stayed in touch with. She’s now finished her college education, she’s now fully employed, and she has the skills she needs to help her kids. When I look at her, in so many ways I see myself, and for me, it’s an example of having fought through it all and being able to reach back and grab somebody by the hand and just say “come on”. I know this is supposed to be a big no no—you don’t let the professional bleed over to the personal. But, I’m a patient advocate and I’m a child advocate and I’m a family advocate and whatever I need to do to ADVOCATE and make that work, I’m going to do. (Staff Interview)

In other instances, the role of patient advocate comes when staff works around rules and regulations so that patients are not hindered from receiving medical treatment due to financial barriers beyond their control.

Julie should bill Medicaid for some of the patients she sees but doesn’t always do that. With the amount of deductible patients have to meet who are on Medicaid, she is always fearful she will cause the patient to have to pay for the screenings if they haven’t yet met their deductibles. “Having to pay deductibles out of pocket when they don’t have the money for health care to begin with would defeat the purpose of our program. If women came here because they couldn’t afford to have the pap and/or mammogram done and then they ended up being charged for the tests, that would create such a hardship. Our patients, especially our older patients, can’t come up with $80 or $100 they weren’t expecting to have to pay.
So, I just don’t bill Medicaid and our patients get the screenings they need. (Field notes)

There have been other situations in which staff has had to be creative to advocate care for needy patients who did not fall within the guidelines to receive free medical care. Peggy and her husband make just over the limit to qualify for free medical care, but when Carol went to her boss and told her about Peggy’s untreated heart condition and her inability to pay for either the medication or the doctor visits, her boss told her to get Peggy in for treatment and she would worry about the money issues later. (Staff interview)

Yet in other instances, staff has had to fight within the medical maze itself in order to advocate for patients who were not able to advocate for themselves due to a lack of knowledge and a lack of resources. Chris, a nurse coordinator, shared the following story about working through multiple layers of bureaucracy to advocate for this patient.

There was a 16-year old girl that I observed in gym class when I was trying to build relationships with school nurses in the area. I noticed the girl had a very large belly and asked her after class if we could talk. I mentioned her enlarged belly and asked if she was worried about it. The girl pulled up her shirt and showed me a mole and said that she thought the mole was cancer and that cancer was filling her up and causing her stomach to bulge. I then asked if she had a boyfriend (yes, he’s in the military) and if she was sleeping with him (yes, but it had been several months ago as he shipped out). I then met with the mother and asked her if she noticed her daughter’s belly getting big. The mom said that yes she did and thought her daughter just might be pregnant. The girl was probably
seven months pregnant by then and had received no prenatal care. I drove her to a
doctor, but she was in such bad shape that no doctors in the area would take on
the liability of treating her. So, I ended up driving her to Cincinnati where she was
admitted to a hospital and kept until she got healthier. Once she was stabilized,
they did a C-section to deliver the baby so it would be born alive. I couldn’t
believe the school nurse had not done anything for this girl. Had I not taken
action, the girl and her baby would have most likely died. (Field notes)

These stories demonstrate yet another method of how CHP staff work to break
down financial barriers and to establish trust within their often marginalized, invisible,
and underserved patient base. They do not simply turn out the lights at the end of their
shift and cop the attitude that the lived experiences of their patients have no importance
to or impact on how they do their jobs. When they have patients in dire need of medical
care, they work around and through the medical maze to advocate a treatment plan that
fits that particular patient’s situation. In the next section, I will provide examples of CHP
staff who adopt the role of cheerleader in order to lend badly needed support to patients
who have no one in their corner.

*Cheerleader.* Along with being navigators and advocates, staff members also find
themselves assuming the role of cheerleader to help their patients stay strong through
treatment regimens or to encourage them to adopt behavioral changes which will lead to
healthier lifestyles. Molly has found that her patients respond positively when she uses
personal stories recounting the triumphs of her former patients. She tells her patients to
think of her as their cheerleader because she will be fighting for them all the way. “I
always say to patients—I’m here as your cheerleader to help you through this—I’m kind
of a navigator to help you find your way through. I’m someone on the sidelines to give you that extra support that your doctor wants you to have” (staff interview). As Molly further explained:

If I can convince patients that other women have been through similar situations and thrived—I try to use personal stories a lot. Sometimes I use generalized things such as “I know other women who have had situations that were very difficult” or “I knew someone who was in a situation like you are and now they’re a counselor. They graduated from high school and made it through college. You can do this too.” A lot of times I’ll use real circumstances but withhold names and places. I try to give them some concrete and real examples to help get them through rough waters. (Staff interview)

Staff members also share their personal triumphs over a medical issue (for example, Julie’s victory over breast cancer) or a personal addiction like smoking to demonstrate to their patients that they too can overcome similar situations. In the following example, Melinda shares her struggle with smoking cessation.

Melinda started the exam by looking in the patient’s ears, nose and throat and then proceeded to listen to her heart and lungs. When she was listening to her lungs, Melinda asked Debbie if she was a smoker. Debbie replied that she was and Melinda asked if she had ever tried to quit. Debbie said that she had quit and started again and that she was always trying to cut down. Melinda shared that she was a past smoker and that she had not been able to quit the first time—actually it was more like the third or fourth try for her. She gave Debbie some tips for
quitting and encouraged her to keep trying because it was so important for her health. “You can do this. It will not be easy, but you can do this.” (Field notes)

Everyone needs someone in their corner cheering them on through illnesses or personal difficulties. For many of the patients served by the mobile clinics, this type of encouragement is seldom encountered in their home environment. The CHP staff has learned to listen carefully to the lived experiences of their patients and understand the need to offer hope and encouragement to those facing an unwanted teenage pregnancy, a behavioral episode from their child, a diagnosis of cancer, or the need to make difficult behavioral modifications. The last category in this section is really a culmination of the other three—that of blurring the lines between health care and people care.

Supporter. Sally believes her patient responsibilities go far beyond referring them to the appropriate agency, physician, or mental health authority. She has also discovered that patients are more willing to be open and honest with her about their own situation when she shares details from her personal history. When asking really tough and potentially embarrassing questions, Sally begins by sharing what has happened in her life and with her kids. She then moves into a discussion about issues like domestic violence and describes how that impacts parenting abilities when one or both parents have been victims of abuse. Many of Sally’s patients are running out of options by the time they are referred to her for evaluation. As Sally explained:

The conversation gets very personal, but they know why I’m asking. They know I need to know in order to get them the help and support they need. And I don’t just say here’s who you need to go see, I set up their appointments, I send through the test results and support documentation, I call to make sure they kept the
appointments, and then I schedule follow-up appointments. I’ve gone to the appointments with my patients if they’ve asked me to go. I’ve followed up with them when I’ve been out of town or on vacation. I am their support system—sometimes I’m the last line between them and a family disaster. (Staff interview)

Other staff members have gone outside the boundaries of the clinic space to make sure that patients receive medications or prescriptions or that they have enough gas to get them to their scheduled appointments. For example, Carol used her lunch hour to go to Wal-Mart to pick up a prescription for a patient who lived in a remote, rural area outside the county. Her intent was to take the prescription and a $30 gasoline voucher (which she was going to buy out of her pocket) to the patient’s home so they could drive into Athens for the medical appointment. Another nurse, Dusty, was familiar with the area and knew there were no name-brand service stations in that area and that a gas voucher from Speedway could not be used. Dusty called the local gas station near the patient’s home to see if they would let her pay ahead for gas since he knew her and her family. The owner agreed to let Dusty bring him money to hold until the patient came to his station to buy gasoline for the trip to the doctor. After work that night Dusty delivered the prescription and the medicine to the patient and stopped at the service station to pre-pay the gas. Carol and Dusty expended a good deal of their own time and money to make sure this patient received needed medical care and social support. (Field notes)

The final story here comes from Sally, a nurse coordinator who works with families and children in crisis. During our interview Sally talked about how her care of patients does not stop at medical or social intervention—her care extends beyond the walls of her office. Sally believes her responsibility is to do whatever she needs to do to
help—whether that is medically, socially, or economically. The following story is a wonderful testament to the trust and ethic of care Sally offers her patients.

I worked with a family who was in a very difficult situation. About four or five months after we got them into services I got a call from dad and he tells me his name and asks if I remember him. I said absolutely and asked how things were going; asked about the family. He tells me that he’s not calling about his family, he’s calling for a buddy who needs some help and he didn’t know who else to call. His friend had lost his job quite a while ago and now the company was calling him back to work. But his friend doesn’t have any tires for his car. He’s got flat tires and no money to get new ones so he can drive to work. I told the dad that I didn’t know the answer his question about tires but to give me a few minutes and I would call him back. I started calling and I started asking people and come to find out the Work Station helps people with cars, with that kind of thing to get to work. I called the dad back and he called his friend and told him where he could get help. Dad called me back to let me know his buddy had gotten tires for his car and he’s back working. So, the thought that the guy would call me and ask about tires for the car—it had nothing to do with my job—but he figured if I went through that much time and effort to help his family, surely I must know where his buddy could get tires! It was really a compliment to what we do here. (Staff Interview)

Summary

There are a number of ways that the Community Health Program attempts to advance an alternate script of health care that acts to reshape the scenes of health care. In
the first section of this chapter, I examined how the (re)organizing of physical and emotional space helps break down barriers to health care by disrupting the meta-narratives that privilege status and promote patriarchy. Additionally, the (re)organization of both space and time helps provide an atmosphere that fosters a sense of community, identification, and consubstantiality among and between the patients and the medical staff. Patients are given the space and the uninterrupted time to talk about not only their health issues, but underlying factors that may be contributing to their illness(es) and/or to the illness(es) of family and friends. By listening to the stories of their patients’ lived experiences of health and illness, the CHP staff are often able to “develop new understandings of ailments or conditions that often contrast with established medically, psychologically, or socially accepted perceptions” (Bosticco & Thompson, 2008, p. 41). Furthermore, patients are subsequently empowered to become the co-owners of their care process instead of merely docile bodies that are subjected to the higher power and the higher authorities of medicine.

In the second section I discussed the blurring of personal (rapport) and professional (report talk) in the front and backstage areas of the clinics as staff shared their personal and family stories of health and healing with patients in the waiting areas and during the medical examinations. This boundary spanning mode of communication resulted in putting patients at ease, helped establish common bonds which broke down feelings of stigma and shame, fostered a sense of community, and helped build connections and trust that often extended outside the physical clinic walls.

In the final section, I described the ways in which the CHP staff continually work outside the boundaries of what is considered traditional biomedical care. Through serving
as navigators, advocates, cheerleaders and support systems, the staff pushes against, expands, and re-writes the organizational scripts that allow some patients to fall through the cracks of the health-care system.

As navigators, medical staff endeavor to make patients feel comfortable and welcome, they assist them with completing complicated forms, and they make referral calls and follow-up appointments. As advocates, the staff works around rules and regulations so that patients are not hindered from receiving medical treatment due to financial barriers beyond their control. As cheerleaders, the staff helps their patients stay strong through treatment regimens, they support their efforts to finish high school or learn a trade, or they support their efforts to adopt healthier lifestyle and behavioral changes. Finally, the staff provide a safety net and a support system that extends to buying gas vouchers with personal funds, arranging to deliver needed medication to patient’s homes, or locating a set of new tires for the friend of a patient so he can get back to work and off welfare.
CHAPTER 6: DISCUSSION

“We should stay on the lookout for marginalized people—people whom we still instinctively think of as “they” rather than “us”...to create a more expansive sense of solidarity than we presently have” (Rorty, 1989, p. 196).

Rorty’s words remind us of the ever present need to be on the lookout for those among us who are marginalized because of their race, religious beliefs, stature, ethnicity, sexual preference, socioeconomic status, or any of the other “isms” that serve to create a chasm between they and us. How we talk about or label the marginalized (see Burke 1954/1984; Duncan, 1999; Goffman, 1963; Lupton, 1994; Prahalad, 2005) can reinforce, reinscribe, and give rise to stigmatization and can lead to tainted or damaged identities (Lindemann-Nelson 2001).

In the context of this dissertation, the marginalized include Appalachian women who, as one Community Health staff member remarked, are the “skeletons in the poverty closet of the United States.” Many of these women have tainted identities because of the stereotypes which position them as poor and lazy. Unfortunately, these tainted identities are accepted not only by people outside the poverty bubble, but sometimes by those living within as well.

The Community Health Program represents a catalytic innovation in health care by providing patients with the physical and emotional space and the necessary time needed to talk about their lived experiences of health and illness. By breaking down the barriers to care, by challenging the status quo of traditional biomedical care, and by working to narrow the chasm of visible (in)visibility patients straddle daily, staff are able
to provide a comfortable, caring, and competent atmosphere in which patients can narrate their lives, positioning illness in broader social circumstances.

The CHP staff members realize the yoke of poverty runs deeply in this region and that it is woven into the very fabric of the culture through religious beliefs, traditions, and familial relationships. The themes offered in this dissertation tell the story of how one organization, the Community Health Program, is attempting to work within the framework of these cultural doctrines to provide a different ethic of care and caring.

My dissertation journey initially emerged from a team research project that I participated in during my doctoral work that studied the shifting scenes and continuity of care provided by the mobile clinics. As I observed the staff and their interactions with patients during this project, I was often transported to a time in my life when my family and I faced many of the same circumstances related to poverty including a lack of insurance, no money for medical treatment, and the presentation of multiple health and illness issues. I was struck by what I interpreted to be a different mode of providing medical care and by the resilience of a patient base who were plagued with numerous health legacies and who had so little in the way of material possessions.

Although I would have embraced the richness that adult male patients would have brought to the study, the majority of the patients I encountered during my observations in the mobile clinics were women living in poverty (the only clinic offered for children was the immunization program so my exposure to them was limited as well). As I immersed myself in the worlds of the mobile health clinic—its rhythms, rituals, and routines—I moved between stories performed and stories told by participants. By drawing on feminist and narrative sensibilities, I provide a rich ethnographic account of how a
counter-narrative of medicine—an alternative web of relations among characters who are living out plots that differ from hegemonic ones—can disrupt the dominant scripts so often taken for granted as natural and fixed, in this case scripts that accompany the biomedical model. Collectively, these insights contribute new knowledge to the body of work in health communication by exploring the standpoints of those who have been rendered invisible through the hegemonic discourses and practices associated with traditional bio-medical care.

Theoretical Implications

The interpretations presented in the analysis of data collected in this study are significant for both communication scholars and medical practitioners. In order to explain this significance, I will explore the theoretical implications of my findings by reflecting on each research question individually. I will highlight relevant themes, issues, and concepts that are important for each question.

Research Question One

The first research question asked: How does narrative activity (if at all) foster healing and empowerment? The synthesis of two specific themes help answer this question: “(Re)organizing space” and “(Re)organizing time.” In addition, the theme of “Blurring Personal and Professional” will be minimally brought into the discussion.

Individuals constitute their identities discursively through the construction and reconstruction of certain narratives of health and illness (Dutta & Zoller, 2005) as “illness is shaped by subjective perceptions, symbolic meanings, and value judgments that arise from an individual’s culture, identity, and environment” (Das Gupta & Hurst, 2007, p xii). The patients who seek medical care from the Community Health Programs free
mobile clinics bring not only medical issues, they bring tainted and damaged identities that are constituted in part by their being labeled as poor, lazy, and undeserving. Recognizing the need to break down a number of barriers (lack of insurance, stigma, fear, flexibility, etc.) that prevent those in poverty from seeking badly needed medical care, the CHP staff approach the medical process as a shared and storied experience by creating a discursive space that allows patients to use narratives to tell of the struggles they encounter in their everyday lives. When patients enter the doors of the mobile clinic, they are invited into a safe and comfortable space where they are provided medical care by staff who do not judge what they have done or their personal situations.

For many of the patients, this is the first time they have ever felt comfortable enough with medical personnel to share their stories of domestic abuse or sexual abuse or to talk about how the death of their spouse or their recent divorce has exacerbated or contributed to a health or illness issue. The lived experiences of health, healing, illness, and chaos are all calls for stories (Brody, 1987; Frank, 1993/1995, Lupton, 2003; Sontag, 1978). This is the first time many of the CHP patients have been invited to share stories about their health, about the chaos in their lives, or about what issues their families are experiencing. This might also be the first time anyone has asked them to share how these lived experiences impact their daily lives. As several staff members reported, patients will usually tell them things that they have never shared with anyone else before. Concomitantly, as relayed by numerous patients, this sharing of lived experiences through narrative fosters not just a sense of physical healing through the medical care to their bodies, but a sense of emotional healing to their minds as well.
Dr. Roberts firmly believes that narrative fosters healing because hearing a patient’s story helps medical staff understand the patient better and aids in how the illness complaint is treated. As he further explained, making time to listen to the story of a patient’s lived experience leads to making better decisions in regard to diagnosis, treatment, care, and the subsequent healing of that patient. Through the account of a patient’s narrative of health and illness, medical personnel are able to transform the details into the clues that will rule out diseases, narrow down the diagnosis, and lead to appropriate treatment (Montgomery, 2006).

From a feminist perspective, using narrative in the context of health and healing, allows the patients (in this case primarily women) to name their lived experiences into existence, to understand those experiences and to ultimately use this knowledge as a means of healing and empowerment. Indeed, numerous patients who came to the clinics ashamed, marginalized, and stigmatized by the conditions of poverty in which they must exist described the sharing of lived experiences as empowering. The telling of stories is empowering as the telling “allows individuals to construct meaning from otherwise devastating life events, repair the disruption caused by illness to their healthy life narrative, and reclaim power from other narratives of the experience, including the medical narrative” (Das Gupta & Hurst, 2007, p. 1). The CHP staff allows patients to maintain their dignity and allow patients to maintain control over what aspects of their story they choose to share. Patients are empowered as they can tell as much or as little of their stories as they want and they can tell their stories their way.

Finally, the CHP staff members help foster healing and empowerment through their willingness to blur their personal and professional identities. The staff found they
could relate to and connect with patients on a deeper level through sharing stories personal stories about their families, hobbies and interests, and personal experiences with health-related issues (for example, surviving breast cancer, struggles with smoking cessation, behavioral issues with children). Letting patients know that they too have experienced similar circumstances levels the playing field, creates common bonds, and allows patients to focus on healing and not on stigma and shame. This theme will be explored more fully in research question two.

Research Question Two

The second research question asked: How is the storied nature of health care shaped by the mobile nature of the clinic? To respond to this question, four themes “(Re)organizing Space,” “(Re)organizing Time,” “Blurring Personal and Professional,” and “Barriers to Care” will be discussed.

One of the ways in which the storied nature of health care is shaped or impacted by the mobile nature of the clinic is quite simply through the physical space of the clinic. The space configuration of the most frequently used mobile van somewhat resembles a traditional doctor’s office with a waiting area, an intake room, and an examination room. However, a major design factor that separates the mobile clinic from a traditional doctor’s office is that patients and staff are not separated from one another by sliding glass partitions, by private lounge areas, or even by private consultation areas. In the mobile van, the waiting area also doubles as office space for the nurse coordinator or whomever is doing the intake and often serves as a consultation area for the nurse practitioner and other CHP staff. The limited space on board the mobile van seems to naturally lend itself to adapting a fluid, interwoven communication between staff and
patients and the sharing of stories evolves. Similarly, clinics held in alternate locations such as the lobby of a church, a small room in a community center, or the hallway of a local school are also limited in physical space. With little to no separation between the patients or between the medical staff, conversation about lived experiences (the election, gardens, children, illness, and so forth) flows freely and people come to know each other on a more personal level—there are no barriers of “us” or “they”.

The concept of (re)organizing space in the mobile clinics takes on a literal and a symbolic significance as CHP staff incorporates both a psychological and social aspect into their health-care protocol. Not only does the warm and engaging physical space invite the sharing of stories, staff members also give patients the personal and emotional space they need during the intake and examination to talk about their health issues and underlying factors that may be contributing to their illness(es) and/or to the illness(es) of family and friends.

By (re)organizing the physical and personal space, CHP staff helps to break down many of the barriers their patient base experience by disrupting the meta-narratives that privilege status and distance between providers and patients. They provide an atmosphere that fosters a sense of community, identification, and consubstantiality among and between the patients and the staff. This sense of community building and the very essence of how story telling is shaped by the nature of the mobile clinic are strongly evident when old classmates use the clinic space to catch up on personal stories, as two former sister-in-laws celebrate the tradition of scheduling their B&C appointments together each year, or as family members and friends gather around the glucose and cholesterol-testing equipment to view and discuss each other’s test results.
Another way that the storied nature of health care is shaped by the mobile nature of the clinic is how “Barriers to Care” are broken down by how health care is provided and by the way care is transported to the people the CHP serve. By traveling to small communities and by setting up clinics in rural and remote locations, the clinic is not just disrupting the barriers of fear, resources, mobility and flexibility, they are also breaking down the barriers of stigma, pride, and marginalization by sending a message that the patients and their stories of health and illness are so important that extra effort is made to deliver health care to their doorstep.

The second theme that responds to this research question is “(Re)organizing Time”. A number of patients reported that the physicians they saw in traditional medical offices did not and would not make the time to ask questions or to listen to their stories. As a result, they felt shut down, shut out, and as one patient said, “treated like they were garbage.” The CHP staff believe in Frank’s (1995) assertion that there is a difference between “taking a patient’s history” and “hearing the patient’s story” and that “time is medicine’s necessary axis” (Charon, 2006).

To ensure they have time to listen, time to recognize, time to care, and time to identify the deeper root causes of a patient’s illness, the CHP staff regularly incorporate information gathering tools such as the BATHE technique into their patient-centered interactions. The BATHE technique is effective because physicians are able to obtain medical histories while probing to see what role a patient’s personal history has on his/her physical and emotional health issues. Since they do not have quotas to fill or billable hours to file, CHP staff do not have to rush patients in and out of the exam rooms. They are made to feel important and valued and they are shown that someone
truly does care about their physical and emotional well being. In short, the nature of the mobile clinic is that it fosters and encourages story telling. As Wendy, a B&C patient shared during our interview, “It’s very important to have someone listen to you ‘cause if you don’t listen, how you gonna fix it? How they gonna treat what may really be causing your problem? Doctors have got to learn to listen to the whole story and not just rush you in and push you out” (patient interview).

The third theme that helps respond to this research question occurs, I believe, because staff members are located in close proximity to patients and because they have adequate time set aside to have deep and meaningful conversations with the patients. This theme is “Blurring Personal and Professional.”

Throughout the various clinics, CHP staff regularly use personal stories to create a common bond with patients and to help ease the sting of stigma, to honor traditions and culture, to preserve a sense of pride and dignity, and to create a comfortable and nonjudgmental space. Many times the incorporation of personal stories by staff form a common ground and open up a reciprocal dialogic thread that compels patients to share their stories as well. Blurring the lines between rapport-talk (sharing personal information) and report-talk (discussing medical issues and treatment), allows medical staff to connect with patients on a deeper and more personal level. Staff often shared their personal experiences with patients, especially when they believed the information would help patients resolve an issue or to let them know that someone understands where they are coming from. When patients learn that the attending physician, nurse, or a member of their family has walked in the same shoes (whether as a breast cancer survivor, a sexual
assault survivor, or a former smoker), patients are more willing to open up and to share their lived stories of health and illness.

Research Question Three

The third research question asked: What symbolic and extra-symbolic forces coalesce in ways that allow women and children living in poverty to be resilient in the face of inhospitable conditions? Although this question is somewhat broad in scope, I believe the first step in responding is to explore some of the barriers that contribute to inhospitable conditions for those living in poverty. The second step in responding to the question will include synthesizing the themes of “(In)visibility,” “Barriers to Care,” “(Re)Organizing Space,” “(Re)Organizing Time,” and “Blurring Personal and Professional.”

The levels of poverty experienced by many of the patients who use the Community Health Program services is staggering and unimaginable to those who have not been exposed to these inhospitable conditions. Considered an (in)visible population, some have been plunged into poverty due to the loss of their job, the loss of their spouse (through death or divorce), or as the result of expenses associated with a catastrophic illness. For others, living in these inhospitable conditions has been the only way of life they have ever known.

Our treatment of those living in poverty is often facilitated by symbolic forces that intersect with corporeal, material, political, and institutional conditions. These symbolic forms, including narratives, construct relationships among people, events, objects, and institutions. The symbolic battle of how to name poverty (Burke, 1954/1984), for example, provides unique challenges because these discursive formations
shape meanings and experiences which can contribute to inhospitable conditions and lead to tainted or damaged identities (Lindemann-Nelson, 2001).

In the context of this dissertation, the women (and by proxy, their children) in the study are often faced with inhospitable conditions. Burns et al. (1997) posited that women as a group are treated differently from men because they usually have less power and fewer resources, have a lower status in the family and community, suffer more frequently from poverty, are denied the education and skills to support themselves, lack access to important health information and services, and lack control over their basic health care decisions. They are often shut down and shut up by people who have some type of power over them and, as a result, feel stigmatized, ignored by society, angry about government bureaucracy, powerless, and alone.

For those living in poverty, narratives represent both a constraining and an enabling symbolic force. The narratives surrounding poverty can be constraining and damaging when they are used to reinforce the stereotypes often associated with the naming of poverty (lazy, degenerate, shiftless, ignorant). As Mumby (1987) suggested, narratives are the principal symbolic form through which organizational structures, policies, ideologies, myths, rituals, and routines are (re)produced and resisted. Narratives can also disrupt the scripts of poverty and social inequity, and as “equipment for living” (Burke, 1941/1967), can bring about dialogue, understanding, and connections.

The CHP mobile clinics provide a physical and discursive space for their patients that enable them to counteract and disrupt the narratives of poverty that act to constrain and damage them. In several interviews, patients reported that CHP staff encouraged them to tell their stories and then listened to them with a nonjudgmental attitude—a
reaction they were not at all used to seeing. Patients also reported that staff took as much
time with them as they needed in order to be able to listen to all their issues—not just
health related—but concerns about housing, food, and family. The sharing of these lived
experiences contributed to that experience by “giving coherence, symbolism, and
meaning to what might otherwise be a chaotic experience” (Das Gupta & Hurst, 2007, p.
1), because “no story sits by itself” (Albom, 2003, p. 10).

In order to build trust and common bonds, the staff members openly shared the
often deeply personal stories of family and of health and illness. The symbolism of
sharing indicated a willingness to look beyond the stereotypes of poverty to see the
human beings living in the shadows of invisibility and to lift them out of the shadows.
And finally, CHP staff went above and beyond merely providing medical care to their
patients. They coalesced into patient navigators, advocates, cheerleaders, and social and
emotional support systems. Through this symbolic and extra symbolic force of
extraordinary care, the staff helped patients be resilient in recovering from serious
illnesses, they helped patients be resilient when facing behavioral issues with their
children, they helped patients be resilient in finding and securing resources for obtaining
additional reduced or free medical care, and they even helped a patient’s friend be
resilient by finding new tires for his car so that he could return to work.

I would be remiss if I did not mention that the patients I met while observing in
the mobile clinics were some of the most resilient women I have ever had the pleasure of
meeting. For example, one woman shared her story of continuing to build a house on her
own because her husband deserted her and her children in the middle of construction. As
I praised her resiliency, she shrugged her shoulders and replied that “you do what you
have to do.” I believe this inner strength, this resiliency, helps women and children survive the circumstances of poverty.

To coalesce means to unite, to blend, to come together as one mass or one community. The Community Health Program coalesces as a symbolic community for those who need a safe haven in which to receive much needed feedback that they are resilient, that they are not lazy or worthless, that they are not (in)visible, and that they will always have someone in their corner.

Research Question Four

The final research question contained three parts which asked: What counter-narratives (if any) does the mobile health clinic offer to disrupt and challenge traditional biomedical and dominant scripts? How (if at all) do these counter-narratives impact the health-care experience for this population? If present, whose interests are served by the counter-narratives? In order to explain how I believe the counter-narratives offered by the mobile clinic disrupts and challenges the traditional biomedical and dominant scripts to better serve their patients, it will be necessary to incorporate and weave examples and conversations from the three themes identified in Chapter 5: “(Re)organizing Space,” “(Re)organizing Time,” and “Blurring Personal and Professional”.

The traditional biomedical approach to medicine, positioned as a grand narrative for understanding health and healing (Morris, 1998), privileges the voice of medicine and marginalizes the voice of the lifeworld (Mishler, 1984). The counterstories, or counter-narratives, offered by the CHP work to alter, disrupt, resist, and challenge these master narratives and dominant scripts by uprooting and replacing them with a better alternative of care (Lindemann-Nelson, 2001).
The first counter-narratives (or alternative script of health care) offered by the CHP involves the (re)organizing of space and time. The physical interior design of the mobile van disrupts the barriers of plaster, protocol, and the sliding glass window that usually separates the patients from the medical staff in a traditional doctor’s office. The patients and staff aboard the mobile clinic are in constant contact with one another as they move between a shared frontstage and backstage area. While this arrangement does sometimes wreck havoc with patient privacy scripts, the physical proximity seems to foster a sense of belonging and acceptance to patients who often are not treated with dignity and respect.

Time is a precious commodity in most traditional medical offices because of patient quotas and the need to produce billable income and patients are frequently herded in and out as quickly as possible. When the patient does finally get to see their physician, they are usually limited to 10-15 minutes and only one chief medical complaint per visit. This “treat and street” approach allows little time for patients to share critical information that will assist the physician in determining the root cause(s) of their illness(es). Realizing the important difference between “taking a patient’s history” and “hearing the patient’s story”, CHP staff attempt to counteract the temporal rhythms of mainstream medicine by allowing for longer patient-physician interaction. They firmly believe that making time to listen leads to better diagnosis, treatment, care, and the subsequent healing of their patients.

The patients I spoke with during my observations and interviews realized the mode of operation within the mobile clinic was vastly different from what they were accustomed to experiencing in a traditional medical facility. They were appreciative of
being treated like human beings with feelings instead of just being treated like a body, and they were appreciative of the kindness, understanding, and extraordinary ethic of care they were given. In this setting, the dichotomy of “us” and “they” has been replaced with a more inclusive approach to health care. The access to quality health care for this population has been significantly enhanced by the presence of the mobile clinic. Since the majority of patients do not have insurance or the financial means to seek health care through ordinary means, the care received through the clinic is often the difference between life and death. The CHP staff often extend the realm of “doctoring” or “healing” far outside the boundaries of the physical clinic walls by setting up clinics in remote areas to reach the most (in)visible patients, by investing their personal time and resources to ensure patients have transportation to appointments, and that patients receive critical medications when they cannot afford to pay for them.

As staff members move between the front and back stage areas of the physical space, they blur the lines between personal and professional talk that opens up space for patients to enter into the conversation. They carry on conversations with patients and each other while discussing the latest medical article on hormone replacement therapy mixed with comments about the cost of gasoline, the latest presidential debate, or their birthday party the previous evening. The master narrative ascribed to the proper behavior in a doctor’s office has been disrupted, indeed, this is not the cold, sterile, silent atmosphere that is typically associated with modern medicine. The staff is able to make connections with their patients by sharing personal stories of their own lived experiences, by establishing common bonds and mutual interests, and by identifying and empathizing with the lived experiences of the patients.
The patients who use the free medical services have tainted and damaged identities from the stigma and stereotypes associated with living in poverty. They are marginalized and rendered virtually (in)visible—the skeletons in the poverty closet of the United States. Although their identities have been narratively constituted and narratively damaged, Lindemann-Nelson (2001) asserted they could be repaired through the use of counterstories. The CHP staff work to restore these damaged identities through navigating, advocating, cheerleading, and serving as social support systems to their patients. By disrupting the counter-narratives and providing an alternative script of health care, the interests of the Community Health Program and its staff are served by being able to deliver quality and timely health care to an underserved population. The interests of the patients are served as they are given access to health care, medication, screenings, and referrals they otherwise would never be able to afford. The interests of the patient’s families are served as their loved ones receive help managing their diabetes or in making behavioral modifications to improve the health. And finally, the interests of society are served because a healthy population is much more cost effective over the long run than one that is plagued with undiagnosed or untreated debilitating illnesses.

Practical Implications

The exploration and explication of the theoretical implications of a research project are essential for advancing understanding within the communication discipline. However, equally important are the practical implications for they offer the researcher a chance to contribute useful and practical information that may evoke positive change, streamline procedures, or open up dialogue for further discussion. Concomitantly, there
are three areas in which the CHP can revise their practices in ways that I believe will allow them to further address the issues of flexibility, visibility, and availability.

During my initial meeting with the director of the CHP, she indicated that they were encountering problems with getting patients to use the services, especially in the clinics conducted in very rural settings. CHP staff members also voiced their concerns with this particular issue—they felt they were providing an affordable, approachable avenue for medical care, but they could not get a high rate of patient participation. As a result, I included questions in my patient interview protocol that I hoped would help uncover specific issues or problems that led to low patient participation. The questions I asked included: How did you learn about this mobile clinic?, If you could change one thing about how the service is offered, what would that be?, Why do you think more patients do not take advantage of the free medical care?, and What suggestions can you offer for getting the word out to more patients?

In response to my question about how she heard about the breast and cervical clinic, one patient responded that she saw a flyer on the door at the local Kroger last year. However, she did not have a piece of paper or a pen to write down the contact number to call for an appointment so she did not come in for a screening. She happened to see a flyer again this year and asked a cashier for a piece of paper and a pen so she could write down the contact information from the flyer. She reported that the stakes were higher this year to seek care because she was worried about some changes in her body. After hearing this story, one of my suggestions to the B&C staff was for them to design their flyers with tear-off tabs that contain the clinic name and the contact number for scheduling appointments. The CHP staff adopted this suggestion and reported that tabs are being torn
from flyers that were posted in various locations. This very practical and simple application was inexpensive to adopt and provides prospective patients with an easier method of initiating contact.

A second question that I asked during the interviews sought to find out why more patients did not take advantage of the various clinics. Along with the larger concerns of patients reporting the fear of receiving bad news, the mentality of “if it ain’t broke, don’t fix it”, a lack of knowledge about qualifying income guidelines, and the concern about their inability to afford follow-up treatment, a frequent response was that people simply do not know about the clinics. Currently the CHP uses public service announcements on the local radio stations and in local newspapers. They also place flyers on bulletin boards in locations frequented by their patient base including laundry mats, libraries, groceries, and senior centers. As patients pointed out though, many of their friends and family cannot afford to purchase a newspaper, do not frequent senior centers, do not shop at the larger supermarkets, and are not loyal radio listeners.

When I asked for ideas or methods of reaching out to a wider audience, patients suggested that word of mouth by current patients to prospective patients would be effective (word of mouth carries weight in the Appalachian culture and would help get at the trust issue as well), they suggested posting flyers at preferred shopping locations such as Wal-Mart or thrift stores and at gas stations and convenience stores that serve smaller communities. Since religion is important to many in the Appalachian culture, patients also suggested partnering with local churches to set up clinics or to pass the word during church services and gatherings. In addition, they suggested running clinics to coincide with local food pantry distributions. Another suggestion for spreading the word is to
increase their partnerships with individual community health departments and with social service venues such as Jobs and Family Services.

In response to the query about what they would change about the current services, patients responded that it was often difficult to get to a clinic during the day because they could not leave their jobs, they did not have child care, or they did not have transportation because someone else in the household needed the vehicle for work. Except for the free diabetes clinics, the majority of mobile clinics are offered Monday through Friday and between the hours of 9:00 a.m. and 4:00 p.m. The CHP staff might want to consider rotating some of their clinics to include weekend and evening hours in order to provide flexibility for patients who cannot access the clinics due to various time conflicts.

The final, and probably broadest, practical implication for the Community Health Program is to increase their presence and visibility. For example, one of the healthy adults programs I observed was held on Saturday morning during the farmer’s market at a local mall parking lot. Even though I knew the mobile van was going to be there, I had to drive around the parking lot twice before I could find where they were located. When I approached the van, there were no signs indicating that free healthy adult screenings were being conducted and there was no one standing outside trying to drum up business. If I could not find a vehicle that large in the parking lot, and if I had not known they were doing free screenings, I would most likely never have known they were present. I made a suggestion to the staff that day that they needed something to make their van stand out such as balloons or music or a staff member standing outside inviting people to come in for a screening. I also suggested they have AmeriCorps students distribute coupons...
throughout the crowd inviting the recipients to come to the van for a free healthy adult screening.

Another two-fold issue impacting visibility occurs when the mobile van is parked at various locations in small communities. On one occasion the van was situated in the rear parking lot of a community grocery store. The van was so far from the main road that traveled past the grocery that only people who knew about the clinic ahead of time would have even known where to look. For another clinic in a small community, the site location was far away from the main street and the van was parked in the rear of an old school where it was not visible to anyone driving past. In fact, I drove past the school twice before I could find the van and I had a good idea of where they were going to be located. In both of these instances, the clinic had not erected any type of banner or signage advertising their services or directing patients to them. To increase their presence in the communities, the clinics need to invest in banners or sandwich boards that can be erected to alert shoppers or passing motorists what kind of services are available at that particular clinic.

Even when the clinics are held in conjunction with county fairs, food pantry distributions, or community health fairs, the CHP does not utilize signage to advertise their services or to direct patients through the process. For example, the CHP set up tables outside the van at a community health fair held at on the fairgrounds of a neighboring city. There were no signs informing people what services the clinic was providing and there were no signs on the various stations to direct patients where to go for the next phase of screenings. Needless to say, the patients were confused about where they were supposed to be and the staff was spending more time giving instructions then
conducting screenings. The clinic ended up being a frustrating experience for patients and staff members and the number of patients screened was reduced due to inefficiency.

My final suggestion for increasing flexibility and visibility is for the CHP to increase their presence in social networks on both a social and organizational level. For example, staff members could establish a regular weekly schedule where they set up healthy adult screenings or childhood immunizations in the lobby of a local Wal-Mart. During these venues, staff members could explain what services are available, provide information about upcoming clinics, and provide income guideline charts so prospective patients would know whether they qualify for free or reduced medical care. In essence, they could provide medical care and engage in public relations in a very visual setting. In addition, CHP staff members need to be encouraged to attend community meetings, public health policy meetings, public forums on health care, or other venues where connections between legislators, financial supporters, potential patients, and community members can be forged and strengthened.

The suggestions offered above are in response to CHP staff concerns that they are not reaching or serving a number of people who desperately need medical care. Although I strongly believe increased flexibility, visibility, and availability will serve as an effective means of outreach to bring in new patients, I am also cognizant that there are some people who will never avail themselves to the free services. No matter how convenient, no matter how well advertised, no matter where the clinics are situated, for some individuals the shame and stigma associated with taking a hand out is stronger than their need for medical care.
A practical implication of the study that goes beyond the scope of just the Community Health Program is the training for future health care providers. Currently, the College of Osteopathic Medicine requires its medical students to shadow and observe on the mobile van and in the free clinics. In addition, medical students are required to practice for a specific period of time within the State of Ohio to provide medical care to underserved populations where access to medical care is scare. The information presented in this, and in similar studies, would be beneficial for helping these future physicians learn and understand more about the Appalachian culture and its people.

Limitations of Study

My immersion into the ordinary routines and conditions under which the CHP staff function allowed me to directly experience (as much as a third party can) how both the patients and the staff conduct their lives while negotiating the constraints and pressures under which they live (Emerson, Fretz & Shaw, 1995). The in-depth interviews I conducted with staff and patients and the observations I conducted in various mobile clinics were extremely fruitful in terms of understanding how the sharing of lived experiences through story telling can create a discursive space for those who often remain invisible.

The CHP staff was extremely welcoming, and because we were able to establish a relationship built upon mutual trust and respect, they were comfortable enough in my presence to talk openly and candidly about the program and the patient base they serve. Because of my interest and background in medicine (I was an emergency medical technician several years ago), and because of the rapport I was able to develop with patients, staff members let me participate in patient intake, observe examinations, and
listen to consultations. In many instances, they explained my project to patients and asked if they would be willing to talk with me one-on-one after the examination was completed. A number of my patient interviews actually took place immediately after the interaction which helped patients more clearly recall specific narratives, events, and reactions. The staff openly answered all my questions during my field work and during in-depth interviews, often sharing deeply personal information to help explain why their work in the clinics is important to them and the individuals they serve. However, there are several specific limitations that I would pursue in a different manner if I were to engage in this study again.

The first limitation is one that cannot be easily remedied given my level of personal and emotional involvement with the participants and the setting. My prior research experience with the clinics and my personal relationships with many of the staff certainly gave me an outsider within status that afforded me access, trust, and further insight into the contexts I investigated and analyzed. However, my own narrative standpoints, which include the pain of poverty and the childhood stigma of being a poor, (in)visible Appalachian female, was ever present and created tensions that necessitated diligence and the use of a reflexive lens for viewing the collected discourses. This is a tension that I embraced and, I believe as a result, I was able to create a safe and comfortable space for patients to share their lived experiences. And, while my account of the storying of health and healing is no doubt shaped by my standpoint and lived experiences, I believe the account is fair and accurate and not overly partisan.

The second limitation was the amount of time I could devote to my fieldwork. Even though I was in the field from May through September, my fieldwork was not
constant in regard to spending a consistent number of hours each week in observations. Because of full-time employment and a family illness, I frequently had to limit my observations to only one or two clinics per week. During weeks when the clinics were conducted in Athens or in a nearby community, I was able to go to work, leave for the clinic hours, and then return to finish the work day. In many instances, however, one day each week was spent traveling to site locations in other counties which meant I devoted an entire day out of the office to allow for travel and observation time. My biggest regret and the biggest limitation in fieldwork resulted from the fact that I was able to observe only one free diabetes clinic as they are offered once every three months. Because of the volume of patients and space limitations, I was able to interview only two of the diabetes patients and both were women. This clinic offers the largest access to male participants and, as a result, would make a good stand-alone research project. Overall, I believe I balanced the array of clinics observed and the number of hours spent in the field well as I traveled over 1,700 miles and compiled over 800 double-spaced pages of field notes and transcribed interviews.

The third limitation of my study focuses on my interview participants. As I mentioned earlier in the dissertation and eluded to above, a key set of voices—male patients—and the richness their perspective would bring is missing from my narrative discussion of lived experiences. Although CHP staff assured me that men did frequently use their free clinics, I only encountered four men throughout my fieldwork (not counting the diabetes clinic). Of those four, I only conducted interviews with two. The first interviewee wanted to talk only about his ex-wife and their messy divorce so I terminated the interview early. The second patient was a student who was getting a physical for the
Peace Corps and did not fit the criteria of the study. The third patient had mental health issues and I was advised not to interview him by CHP staff. The fourth patient was extremely ill the day of his appointment and was referred immediately after his examination for further testing due to the suspicion that he might have stomach cancer. Another group that I would like to have included in personal interviews but simply could not do so due to time constraints were the higher stakeholders such as the physicians in the free diabetes clinics, the dean of the medical school, and the state representatives who control much of the funding for the Community Health Programs.

The final limitation (an ethical, moral and emotional one) of this study is seemingly inherent in the methods and theories used to collect data from my research participants. My job, if you will, was to ask the vulnerable—those in poverty—to potentially make themselves even more vulnerable by allowing me to hear their health issues, to witness their physical examinations, and to open up their private lives to share often painful, stigmatizing, or embarrassing narratives with me. Throughout this process, I made a conscious decision to reveal my background to the patients so they knew I personally understood their lived experiences and the circumstances surrounding those experiences. I tried to be sensitive and to protect the stories and vulnerabilities of my research participants. Although the power of narratives can be very useful, they can also have negative impacts if not handled or respected properly. I truly feel the participants who shared their lived experiences with me knew that I would treasure and cherish their stories and that I would share them wisely and with compassion.
Directions for Future Research

The OUCOM mobile health clinic offered a unique opportunity to empirically enrich narrative literature through exploring the storied nature of health and health care amidst ever-shifting scenes of activity. The continuously shifting terrain of health care calls for updating the ways in which we come to understand and study health communication phenomena (Dutta & Zoller, 2005, p. 5) and narrative form creates an opportunity to advocate for health care reform (Conrad & Millay, 2001, p. 157).

Our charge as engaged communication scholars within the academic realm is to constantly challenge current methodologies and theoretical underpinnings and to explore the discursive nature of social problems linked to issues such as poverty. We must engage our messages “with the complexities of human needs, motivations, and priorities” (Dutta & Zoller, 2005, p. 1).

As engaged communication scholars in the public realm or in the field, our first charge is to do no harm as we immerse ourselves into the personal, private, and work lives of those we study. We also have an obligation to give something back to the people, organizations, and stakeholders who willingly invite us into their spaces and trust us with their stories. This giving back might include working beside health care professionals to lobby for much needed health-care reform, helping research potential sources of funding, or lobbying for changes in the poverty guidelines which determine who qualifies for free or reduced medical care.

Well informed and well conducted research naturally generates questions as it seeks to find answers. Generally, I believe the insights discovered from this study support and confirm the need to extend the communication discipline’s theoretical and practical
reach to include alternative forms (such as the mobile health clinic) of organizing health care and health care resources. The involvement of communication scholars in social problems, both locally and globally, is important and will continue to advance and nurture the discipline. As a communication scholar and, as a child of Appalachia, this project whetted my appetite to continue to study within the realm of health communication and to work with organizations that contribute to the betterment of society through social change.

I understand that critics might take me to task for romanticizing or celebrating the work of an organization that exists solely because a segment of the population has limited access to quality health care. Critics might also point out that no matter how competent the CHP staff are in advancing an alternate script of care, patients walk away from treatment still needing food, clothing, and shelter. I appreciate and embrace these criticisms for they offer an opportunity to continue our dialogue and to enrich and further scholarly inquiry.

This project only undertook one aspect of the Community Health Program—the storied nature of lived experiences for women using the free clinics. However, the project has stimulated questions for further study of the CHP services in a number of related areas. First, as I mentioned previously, the male voice and perspective are absent from this study because of a lack of opportunity to observe or to interview the few male patients who used clinics in which I was present. Therefore, a study that focuses on eliciting the lived experiences of men living in poverty who are driven by economic factors into using the free medical and diabetes clinics would be an interesting contrast and comparison. Questions to consider is a study of this nature include exploring whether
men experience the same feelings of shame, marginalization, stigmatization, consubstantiality, identification, and common bonds described by female clinic patients. I also wonder whether men would avail themselves to resources such as a prostrate cancer screening clinic if the CHP were to begin those services. One of the nurses remarked to me that men only come to the free medical and diabetes clinics because their wives make the appointments and insist they seek medical treatment. The exploration of this study could combine gender, health communication, and narrative from a feminist perspective.

A second direction for future research would be to further explore the concept of the BATHE technique and Stuart and Lieberman’s (2002) premise of the 15-minute hour within the traditional biomedical model. Like Stuart and Lieberman, Dr. Roberts from the mobile clinic firmly believes that taking a patient’s history and listening to a patient’s story about their lived experiences of health and healing can give physicians a much better idea of the underlying cause of illness(es) in a very short period of time if the right sequence of questions is used. An interesting project would be to observe doctors who subscribe to the BATHE technique and those who adhere strictly to the traditional biomedical protocol of history taking. As Frank (1994) suggested, “many distinguished physicians throughout medical history have certainly emphasized listening to the patient, but…the logic of medical practice is such that doctors have had to be reminded of what should, from a naïve perspective, be central to medicine” (p. 2).

The final direction of future research would be to work with the CHP and other health care providers to elicit reforms in health care and funding formulas. For example, the current poverty guidelines that the CHP must follow to qualify patients for free or reduced care are unrealistic (see Table 2). The majority of the clinics are available only to
patients who are 150-200% below the poverty level as determined by the State of Ohio. This poverty scale presents yet one more barrier to many people in desperate need of medical attention. Hopefully this study would not only help knock down the walls of economic injustice, but would also give those caught in the web of truly invisible poverty a space to voice their lived experiences.

My Journey with the Community Health Program

The staff of the Community Health Program consists of some of the most caring and inspiring people with whom I have ever had the pleasure to work. I was humbled by their warmth, acceptance, and willingness to embrace me and to include my research project into the day-to-day workings of the Community Health Programs. I looked forward to the time I spent observing in the various clinics, interacting with staff, and meeting and talking with patients. I enjoyed the camaraderie and friendship that developed between me and the CHP staff and look forward to our continued lunches and email correspondence.

My observations were not just conducted by plopping myself down in the corner of the waiting area to watch as patients filed through the door. Instead, while I was watching and listening as an interpretive, reflexive researcher, I got to observe the nurse practitioner perform pap tests and breast exams. I got to hold children and calm them before and after their immunizations. I got to help carry tubs of screening supplies, set up screening areas, direct patients as they moved through various screening stations, distribute and explain educational materials, and learn about the staff’s children, spouses, and interests outside their jobs. I was able to build rapport with patients while they were waiting to be examined, and they often shared their fears of the medical procedures, their
embarrassment of being there, their preference to not have students present during examination, or their preference to not be examined by the male doctor on board that day. I was able to serve as a patient liaison with the CHP staff as I shared the patients’ stories when relevant to their care or as I passed along their fears and their preferences before they were ushered into the examination room. I truly felt useful and was deeply immersed in and invested in the program and in the patients served. When the time came to step out of the observation and interview mode and into the analyzing and writing mode, I did so with reluctance and sadness because I knew I would miss my colleagues and I would miss talking with and learning from the patients.

Even though I thoroughly enjoyed the time I spent with the CHP patients, there were difficult times as well. As I witnessed the physical condition of some of the patients (toothless, ragged clothing, poor hygiene) and heard their heartbreaking stories of marginalization and stigmatization, I could not help but be transported back to my own lived experiences with poverty. One such occasion occurred during an observation in the OB/GYN office with a young pregnant woman named Rose.

*I asked Molly for some background information on Rose before we went into the exam room to talk with her. Molly said that Rose was a handful—she knew it all and no one could tell her anything. She continues to smoke heavily throughout the pregnancy and the smoking cessation nurse has been working with her with no luck. Molly also said that Rose seldom talks as her mother, who never leaves her alone during an appointment, does most of the talking for her.*

*Rose and her mom were in the exam room when Molly and I entered. Rose had on short red stretchy shorts and a red short-sleeved tank top that barely*
covered her stomach. Her mom had on flowered shorts and a mismatched smock top. From their dress and their speech, it appeared that these were very poor people. They reminded me a lot of some of my relatives and I could not help but be drawn to them. I also could not help thinking that although Molly and Dr. Brooks were not happy with the role Rose’s mom was playing, unlike another patient from last week whose parents had disowned her, at least Rose’s family were sticking by her.

Later on that afternoon in the staff lounge, two of the physicians’ office staff members were talking about how difficult Rose and her mother are to work with and how bad they smell. I found myself feeling very uncomfortable listening to them “trash talk” about Rose as I remember what it was like to be teased about stinking when I was growing up because we only took a bath once a week. I also remember what it is like to be with relatives who have no teeth, whose English is laced with bad grammar, and who do not dress well in social settings. Many of the patients I met during my observations reminded me of people in my life and it was difficult to distance myself and remain objective.

More than once I broke into tears as I discussed my field work with my dissertation chair for the patients’ stories resonated with and re-awakened stories of my own life. Their pain parallels, in many ways, my own pain. There were stories that caused flashbacks to incidents that had happened during my childhood and that invoked discomfort and dissonance. When weaving the stories of my lived experiences throughout this dissertation, I chose carefully how much personal information to reveal to my colleagues and to those who will read this dissertation in perpetuity. For you see, the
ghosts of fear and shame, and the stigma associated with poverty are never completely eradicated from how you act or react even when you have been able to lift yourself out of the shadows of being visibly (in)visible. However, the journey was so worth every moment of discomfort I experienced.

Through hearing the patients’ stories, I came to realize that, while we were poor, we never went hungry, and we never went without having a roof over our heads. I never had to worry about my parents being incarcerated or to hide the bruises from being beaten. Indeed, my heart was gladdened as I learned of the resiliency and humanity of these people who were very often down to their last bucket of hope. And, I hope that I was able to offer something in return—a kind word, to share a mutually lived experience so they knew I understood, and to convey that they were deserving of the medical care they were receiving from the CHP.

Throughout my journey, I have contributed feedback to the CHP staff and their director about ways to improve their processes and about ways to provide even better medical care to their patients. I have also written or co-written three mini stories about the services offered by the CHP that have been used on their web site, in preparing grant applications, and for internal and external reporting and public relations. I also worked with the CHP perinatal coordinator and the partnering OB/GYN practice to write a mini story for the physicians’ use in patient education and for educating the medical community at large. In addition, at the request of the CHP director, I conducted research, prepared charts and graphs, and prepared an application for the prestigious Monroe E. Trout Premier Cares Award (which we unfortunately did not win).
Once my dissertation defense is completed and my dissertation is bound and placed in the library, I will offer a synopsis of my findings at a CHP staff meeting and to other constituents as identified by the director. My intent is to remain involved with the CHP program and to use my voice and my knowledge to lobby for health care reform, to help the CHP apply for grants and additional funding, and to continue to provide those who are (in)visible a space in which to tell the stories of their lived experiences.

Although the Community Health Program staff is changing the face of health care for this underserved population, there are times when it is not easy or possible to perform an alternative script of health care. Rules and regulations get in the way, socioeconomic situations pull at already overburdened budgets, the patients still do not trust or feel empowered, and the toothless are still toothless. And, unfortunately, all the free medical care in the world isn’t going to help provide patients with food and shelter. So, my friends, colleagues, and fellow communication scholars—there is still much important work to be done. Let us roll up our collective sleeves and continue our efforts to education, to advocate, and to provide a voice for those who otherwise continue to be silenced and who would continue to remain (in)visible.
REFERENCES


Goodall, H.L., Jr. (2000). *Writing the new ethnography*. Walnut Creek, CA: Altamira.


Green, M.C., & Brock, T.C. (2002). In the mind’s eye: Transportation-imagery model of narrative persuasion. In M.C. Green, J.J. Strange, & T.C. Brock (Eds.), *Narrative impact: Social and cognitive foundations* (pp. 315-341). Mahwah, NJ: Erlbaum.


*Communication Quarterly, 43*(2), 210-224.


*Communication Monographs, 54*, 113-127.


*Social Science Quarterly, 69*, 874-891.


Table 1

Demographics: Patient Marital Status

<table>
<thead>
<tr>
<th>Married</th>
<th>Widowed</th>
<th>Divorced</th>
<th>Single</th>
<th>Unknown</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>33</td>
<td>13</td>
<td>20</td>
<td>14</td>
<td>9</td>
<td>89</td>
</tr>
</tbody>
</table>
Table 2
2009 United States Poverty Guidelines

<table>
<thead>
<tr>
<th>Persons in Family</th>
<th>Poverty Guideline (100%)</th>
<th>Poverty Guideline (150%)</th>
<th>Poverty Guideline (200%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>$21,660</td>
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<td>$49,905</td>
<td>$66,540</td>
</tr>
<tr>
<td>8</td>
<td>$37,010</td>
<td>$55,515</td>
<td>$74,020</td>
</tr>
</tbody>
</table>

Note: Those in the 150% poverty bracket are eligible for the free clinics. Those in the 200% poverty bracket are eligible for the Ohio breast and cervical cancer program.
OHIO UNIVERSITY
College of Osteopathic Medicine

Community Health Programs
Evans Center Room 117
Athens, Ohio 45701-2979
T: 740-593-9431
F: 740-593-9431

April 8, 2008

Ohio University
Institutional Review Board
Research & Technology Center
Room 117
Athens, Ohio 45701

Committee Members:

Please accept this letter as confirmation that I have granted access to conduct participant observations at activities of the Community Health Programs of OUCOM as well as in-depth interviews with staff to Karen Deardorff, a doctoral student in Communication Studies. If I can provide any other information, please feel free to contact me at ktrace@ohio.edu or 593-9354.

Sincerely,

Kathy Trace
Director, Community Health Programs
APPENDIX B: OHIO UNIVERSITY INSTITUTIONAL REVIEW BOARD (IRB)

PROJECT OUTLINE FORM

Title of Research Proposal: Catalytic Innovations in Appalachia Ohio Health Care: The Storying of Health Care in a Mobile Clinic

INVESTIGATOR(S) INFORMATION

Primary Investigator
Name  Karen Deardorff  Department  COMS
Address  201 Trisolini
Email deardorf@ohio.edu  Phone  593-4275
Training Module Completed?  X Yes  No

Co-investigators
Name  N/A  Department  
Address  N/A
Email  N/A  Phone  
Training Module Completed?  □ Yes  □ No

Advisor Information (if applicable)
Name  Dr Lynn M. Harter  Department  COMS
Address  Lasher Hall 109  Phone  593-4830
Email harter@ohio.edu
Training Module Completed?  X Yes  No

Anticipated Starting Date  May 15, 2008  Duration  12 mos 0 yrs
(Work, including recruitment, cannot begin prior to IRB approval. This date should never precede the submission date)

Funding Status
Is the researcher receiving or applying for external funding?  □ Yes  X No
If yes, list source  N/A
If yes, describe any consulting or other relationships with this sponsor.  N/A

Is there a payment of any kind connected with enrollment of participants on this study that will be paid to persons other than the research participants?  □ Yes  X No
(If yes, describe.)  N/A
Review Level
Based on the definition in the guidelines, do you believe your research qualifies for:

- [ ] Exempt Review Category
- [ ] Expedited Review Category
- [X] Full Committee Review

Recruitment/Selection of Subjects
Maximum Number of Human Participants: 100

Characteristics of subjects (check as many boxes as appropriate).
- [ ] Minors
- [ ] Physically or Mentally Disabled
- [ ] Elementary School Students
- [X] Adults
- [ ] Legal Incompetency
- [ ] Secondary School Students
- [ ] Prisoners
- [ ] Pregnant Females
- [ ] University Students
- [X] Others (Specify) Ohio University Employees

Briefly describe the criteria for selection of subjects (inclusion/exclusion). Include such information as age range, health status, etc. Attach additional pages if necessary.

Participants will be selected for inclusion in this study based on their involvement with the Ohio University College of Medicine’s Community Health Program (CHP), including the mobile and free clinics, the healthy adult programs, childhood immunization programs, and breast and cervical cancer screening program. Participants will come from various populations within this group and will include patients, staff members, parents of patients (for childhood immunization program), caregivers and/or significant others of patients, and administrative stakeholders of the CHP.

How will you identify and recruit prospective participants? If subjects are chosen from records, indicate who gave approval for the use of the records. If records are "private" medical or student records, provide the protocol, consent forms, letters, etc., for securing consent of the subjects for the records. Written documentation for cooperation and/or permission from the holder or custodian of the records should be attached. (Initial contact of subjects identified through a records search must be made by the official holder of the record, i.e. primary physician, therapist, public school official.)

Some of the participants in this study will be staff members of various Community Health Programs through the Ohio University College of Osteopathic Medicine. I will be observing and interviewing the program director, physicians in the free clinics, registered nurses, mobile health van drivers, nurse practitioner, and a certified medical assistant. No recruitment will be necessary for this group, however, their participation in the interviews will be voluntary. I have received permission from the director of the program, Kathy Trace, to participate in all clinics offered by the CHP (see attached letter, Appendix E).

Patients will be recruited during on-site observations in the various programs offered by the CHP. In many instances, I will be observing the interactions between patient and medical personnel. Permission to observe medical interactions will be obtained by
verbal and written consent of the patients prior to each observation. Patients will also be given a letter inviting them to participate in one-on-one interviews with me. These interviews will be set up at a time and location convenient for the research participant. All participation will be on a voluntary basis and written consent will be obtained prior to beginning interviews.

Caregivers and/or significant others: When observing in the childhood immunization programs, I will often have the opportunity to talk with parents while they are waiting for their child(ren) to receive vaccinations. I will obtain written consent before interviewing parents about their involvement in the clinics. No children will be interviewed. Caregivers and/or significant others may be interviewed if their presence plays a significant role in overseeing the patient’s care or support. Written consent will be obtained prior to the interviews.

Please describe your relationship to the potential participants, i.e. instructor of class, co-worker, etc. If no relationship, state no relationship.

Participants have no direct relationship to the primary investigator. The organization knows of my intent to study them and my position as a researcher will not be withheld from anyone. The researcher will be a volunteer to assist staff as directed during observations.

Attach copies of all recruitment tools (advertisements, posters, etc.) and label as APPENDIX B. See letter that will be given to patients inviting them to participate in interviews.

Performance Sites
List all collaborating and performance sites, and provide copy of IRB approval from that site and/or letters of cooperation or support.

Data collection will occur on the Community Health Program mobile health unit and the free clinics held at the Stewart Community Center and at Parks Hall. See letter of approval obtained from Kathy Trace, Director of Community Health Programs (labeled Appendix E). Interviews with patients and their caregivers/significant others will occur at locations deemed convenient by those being interviewed.

Project Description
Please provide a brief summary of this project, using non-technical terms that would be understood by a non-scientific reader. Please limit this description to no more than one typewritten page.

My dissertation, overseen by Dr. Lynn Harter, will involve observing mobile and fixed clinics conducted by the Community Health Program in the College of Osteopathic Medicine. I will observe the Community Health personnel as they interact between and
among themselves and their patients. I will also observe how patients tell their stories of illness, health and healing to health-care providers.

Please describe the specific scientific objectives (aims) of this research and any previous relevant research.

My research will look at how narratives are used to create identification and consubstantiality with patients, how personal and professional boundaries are managed, how medical care is improvised in shifting spaces and locations, patient privacy issues, and frontstage/backstage interactions among Community Health Program staff as they provide healthcare services.

I will draw upon feminist and narrative sensibilities to provide an ethnographic account of the Community Health Program and its endeavor to address the poverty and health-related issues of the patients they serve. I will seek out patterned regularities in the way participants’ account for their lived experiences of health and healing as well as counter evidence and alternative viewpoints. My goal is to negotiate and open up a discursive space that allows the participants (patients, staff, and stakeholders) to tell their stories of health and healing. My aim is to provide a vehicle through which those stories can disrupt and challenge the traditional biomedical models of health care and spark additional dialogue.

Methodology: please describe the procedures (sequentially) that will be performed/followed with human participants.

The research procedures for this study fall under three broad categories. They will be treated in the rough order of their implementation below. However, qualitative research is often an iterative process where researchers simultaneously employ multiple methodologies.

Participant Observation: Participant observation, noted by ethnographers as a key element to any study that calls itself ethnography or claims to be guided by ethnographic principles, involves getting close to the participants of particular social settings (Emerson, Fretz, & Shaw, 1995; Lincoln & Guba, 1985; Lindlof & Taylor, 2002; Lofland & Lofland, 1995). In essence, participant observation is research by doing. For this study, I adopt what Lindlof and Taylor (2002) term a “participant-as-observer” (p. 147). This method involves openly acknowledging my role as a researcher with an ability to “study a scene from the vantage point of one or more positions within its membership” (p. 147). As a participant observer with the Community Health Program, I will accompany staff members on the mobile health unit trips and during the free clinics in order to immerse myself into the real-world, operational experiences and challenges faced by staff members as they provide care to an underserved population. During the clinics, I will observe the interactions between Community Health Program staff and between staff members and the constituencies they serve. I will also observe staff and patient interactions during healthy adult screenings and childhood immunization clinics.
After each field observation, I will prepare field notes which will be analyzed and thematized after I believe enough data has been collected to start the process.

In-depth Interviews: Participant interviews are a logical mechanism through which to allow participants to account for their experiences. As Holstein & Gubrium (2003) argue, “interviewing provides a way of generating empirical data about the social world by asking people to talk about their lives” (p. 3). In-depth interviewing is a qualitative research technique that allows people to describe the ways in which they understand their world, the ways in which they make sense out of their world, and it allows them to account for their experiences. After completing several hours of observation, in-depth interviews will be conducted with Community Health Program staff (nurse practitioner, RN’s, certified medical assistant, two van drivers) and adult patients. The interviews will be guided by the tentative protocols attached; however, I will allow sufficient space for the unique stories of individuals to emerge and will revise the protocol while I am in the field and as unintended issues emerge that merit attention. All interviews, with participants’ permission, will be audio recorded digitally. If a participant agrees to have his/her interview recorded, it will be transcribed in its entirety. If a participant does not agree to be recorded, notes will be taken both during and after the interview. The transcripts and notes from the interviews will be examined and thematized.

Document analysis: Like interviews, document analysis is strongly connected to participant observation. Documents are artifacts that are critical to the functioning of organizations, groups and individuals and can provide historical context, corroborate observations and interview data, evoke new questions or ideas and provide data that is not available in any other format (Glesne, 1999; Lindlof & Taylor, 2002). Documents by themselves can have limited significance (Lindlof & Taylor, 2002); however, when related to other types of evidence, document analysis can prove to be an enlightening method of data collection. Document analysis can be linked to, and confirm, “the talk and social action contexts that the researcher is studying” (Lindlof & Taylor, 2002, p. 117). Documents can help to recreate past events that the researcher is unable to observe and they “endure and thus give historical insight” (Hodder, 2000, p. 704). Lastly, documents “reflect certain kinds of organizational rationality...they often embody social rules...that govern how members of a social collective should behave” (Lindlof & Taylor, 2002, p. 117).

Documents that will be considered artifacts for analysis for this study will include, but are not limited to: memos, previous research studies, training materials, organizational policy handbooks, published articles about the Community Health Program, clinic advertisements, and informational pamphlets.

Describe any potential risks or discomforts of participation and the steps that will be taken to minimize them.

There are no known risks to involved participants and all participation will be on a voluntary basis. Staff members and the patients they serve may be uncomfortable interacting in the presence of an outsider. Community Health Program staff are
acquainted with the researcher based on previous interactions with them and are familiar with my interest in the mobile health and free clinics.

In order to minimize any discomfort experienced by patients, I will obtain verbal permission from the patients via the nurse practitioner, certified medical assistant, or registered nurses before observing the interactions. If there is any doubt as to the comfort level of the patient or staff member, I will not observe that particular interaction or clinic.

Patients will be invited to participate in in-depth interviews with the researcher via a letter. Interviews will be conducted in a location preferred by participants in order to provide a comfortable environment.

No types of deception will be used with either staff or patients. My role as a researcher will be known by all participants.

Describe the anticipated benefits to the individual participants. If none, state that. (Note that compensation is not a benefit, but should be listed in the compensation section on the next page.)

The Community Health Program provides an amazing service to the underserved population in the counties covered. Through this research project, I hope to be able to provide the staff with information and data that will serve them well in preparing grant proposals and funding applications. They anticipate that my research project will lead to a better understanding of the needs of their patients and will provide a better understanding of the services they provide by the constituencies they serve.

Describe the anticipated benefits to society and/or the scientific community. There must be some benefit to justify the use of human subjects.

I have agreed to use my research findings to help Community Health Program staff in preparing grant proposals and funding requests, to work with them in identifying additional locations to set up mobile clinics and to help identify additional sources of advertisement for getting the word out to potential patients. I have also agreed to write mini articles that the staff and director can use as publicity pieces to advertise their services, to share with state, local, and national government officials to reinforce the need for additional funding, and to share the stories of their successes with clients, with the media, and with other health-care organizations.

Ultimately, my hope is that the results of this research project will in some way help the Community Health Program provide enhanced and/or additional services to a desperately underserved population.

Please discuss the level of confidentiality, if any, honored for the data collected. For example, indicate whether records will be labeled with the subject’s name, or whether
they will be labeled with a code number, with a master key that links name and code number maintained in a separate and secure location.

The field notes, audio tapes, and transcribed interviews will be viewed only by the primary researcher. All notes and transcriptions will be kept on the password protected personal home computer of the researcher and/or in a locked file cabinet drawer for which only the researcher has the key.

To protect the privacy of the research participants, pseudonyms will be used in the place of actual names and the actual clinic locations will be altered for all observation field notes used in the dissertation writing project. The raw data and transcripts will not be provided to any party who might be able to connect a person with their specific answers. All interviewees will be made aware of the confidential nature of the interviews and the anonymous nature of the interview transcripts.

The transcripts of personal interviews with patients will only contain pseudonyms. Any contact list containing address, phone numbers, and patient identities will be shredded once interviews have been conducted. For staff members who may be invited to participate in member checking, their transcript (with a pseudonym) will be cross referenced to a list containing their true identity. Once the member checking session is complete, this list will be shredded and only the pseudonyms will remain.

With whom will identifiable data be shared outside the immediate research team? For each, explain confidentiality measures.

Only the primary researcher and perhaps the dissertation director will have access to the raw data. However, the dissertation director will most likely review the transcripts once they are created and they will have no identifying characteristics and will contain pseudonyms and altered locations. If requests for data are made, only the anonymous transcripts will be provided.

Will participants be: Audiotaped?  X Yes  □ No

Videotaped?  □ Yes  X No

If so, describe how/where the tapes will be stored (i.e. locked file cabinet in investigator office), who will have access to them, and an estimate of the date they will be destroyed.

Interviews will be conducted using a digital voice recorder. The recordings will be downloaded onto the researcher’s personal home computer using Digital Voice Editor software. Once the recording has been transcribed, the digital recording and the computer recording will be erased. My computer is password protected, meaning that the data will be accessible only to the researcher. Once all audio files have been transcribed, the original files that identify the participants by name will be deleted and only the anonymous transcriptions will remain.
Provide details of any compensation (money, course credit, gifts) being offered to participants, including how the compensation will be prorated for participants who discontinue participation prior to completion.

*There will be no compensation for participants in this study.*

**Instruments**
List all questionnaires, instruments, standardized tests below, with a brief description, and provide copies of each, labeled as APPENDIX C.

*A list of possible interview questions for Community Health Service staff and stakeholders is attached and labeled Appendix C1. Likewise, a list of possible interview questions for patients is attached and labeled Appendix C2. These instruments have been constructed with question areas I am interested in pursuing during my field observations. These instruments will be used to conduct in-depth interviews with the staff and patients after several hours of field observation and may be altered slightly depending on the outcome of those field observations.*

How will the data be analyzed? If applicable, state the hypothesis and describe how the analysis of the data will test that hypothesis.

*As this is a qualitative analysis of narrative communicative processes, no formal hypotheses are posed. However, my research questions are provided below. Answers to these questions will hopefully emerge from the data that is collected from all respondents.*

**RQ1:** How does narrative activity (if at all) foster healing and empowerment?
**RQ2:** How is the storied nature of health care shaped by the mobile nature of the clinic?
**RQ3:** What symbolic and extra-symbolic forces coalesce in ways that allow women and children living in poverty to be resilient in the face of inhospitable conditions?
**RQ4:** What counter-narratives (if any) does the mobile health clinic offer to disrupt and challenge traditional biomedical and dominant scripts?

**RQ4a:** How (if at all) do these counter-narratives impact the health-care experience for this population?
**RQ4b:** If present, whose interests are served by the counter-narratives?

*After observing in the clinics for approximately five months, the researcher plans to interview key staff of the Community Health Program and patients from various clinics. The instruments labeled Appendix C1 and C2 will be used to provide a baseline for probing into specific areas of research interest. The researcher will conduct the interview sessions and will be responsible for transcribing the audiotapes. The researcher will read transcripts to see if themes emerge that correlate with my areas of interests.*
The constant comparative method (see Glaser & Strauss, 1967) will be used to conduct a thematic analysis of the discourses collected through in-depth interviews, participant observations and document collection. The researcher will read all field notes and transcripts in their entirety to develop a sense of the discourses as a whole. After gaining a holistic sense of the discourses, the researcher will start actual analysis.

Member Checking or member validation (Lindlof & Taylor, 2002) is a process in which qualitative field researchers verify their interpretation of a social setting with selected members of that setting. The underlying belief of member checking is that social actors are capable of making sense out of their own world. I will use member checking to take my findings back to the field to determine whether the participants recognize them as true or accurate. Member checks generally involve asking participants questions such as: “What did I get wrong?” “Have I been fair?” “What else should I add?” By asking these types of questions, researchers are able to gauge to what extent the scholarly interpretation of the setting rings true with those who actually experience it. Member checks exist not to make sure the researcher is right, but to make sure that the researcher’s interpretation overlaps to some extent with how social actors view their world. Member checking sessions can also result in additional information that can help the researcher continue to analyze a setting or pick up on something that might have been missed initially (Lindlof & Taylor, 2002).

Informed Consent Process
Are you requesting a waiver or alteration of Informed Consent? □ Yes  X No
(If yes, check one, and answer a - e)
□ Waiver of signature
□ Deception (incomplete disclosure)
□ Complete Waiver of consent

a. Provide justification for the waiver. N/A
b. Describe how the proposed research presents no more than minimal risk to participants. N/A
c. Why will a waiver of informed consent not adversely affect the rights and welfare of participants? N/A
d. Why is it impracticable to carry out the research without a waiver or alteration of informed consent? N/A
e. How will pertinent information be provided to participants, if appropriate, at a later date? N/A

Even if waiver of written informed consent is granted, you will likely be required to obtain verbal permission that reflects the elements of informed consent (if appropriate).

Please specify below information to be read/given to participants.

N/A
Attach copies of all consent documents or text and label as APPENDIX A. Please use the template provided at the end of this document.

Informed consent is a process, not just a form. Potential participants/representatives must be given the information they need to make an informed decision to participate in this research. How will you provide information/obtain permission?

The researcher will provide the informed consent form at the time of the interview, explain the interview process, and allow the potential participants to choose whether or not they would like to participate. All participants will be given a copy of the interview protocol prior to the interview and will be asked to read the questions. Participants will be told before the interview that any questions they do not want to answer or feel uncomfortable answering can be skipped. An informed consent form will be discussed and signed when/if the interviewer and interviewers meet prior to beginning with the first interview question.

How and where will the consent process occur? How will it be structured to enhance independent and thoughtful decision-making? What steps will be taken to avoid coercion or undue influence?

The researcher will provide the informed consent form at the time of the interview, explain the interview process, and allow the potential participants to choose whether or not they would like to participate. Participants will be told before the interview that any questions they do not want to answer or feel uncomfortable answering can be skipped. The consent form will be written in clear, non-scientific language and will describe the nature of the study. The researcher will assure the participants that participation is completely voluntary and that choosing not to participate will in no way affect their relationship with the researcher, faculty, administration, or any other party.

The consent process will include the independent thought of the interview participants because they will have multiple (2-3) opportunities to agree to the interview process, ask questions of the researcher, and opt out of the interview.

Will the investigator(s) be obtaining all of the informed consents? ☑ X Yes ☐ No

If not, identify by name and training who will be describing the research to subjects/representatives and inviting their participation?

Will all adult participants have the capacity to give informed consent? If not, explain procedures to be followed.

Yes, as far as I know, all participants will have the capacity to provide informed consent.

If any participants will be minors, include procedures/form for parental consent and for the assent from the minor.

No participants will be minors.
Will participants be deceived or incompletely informed regarding any aspect of the study? □ Yes  X  No

If yes, provide rationale for use of deception. N/A

If yes, attach copies of post-study debriefing information and label as APPENDIX D. Additionally, complete the questions related to a consent form waiver or alteration on page 9. N/A

Investigator Assurance

I certify that the information provided in this outline form is complete and correct.

I understand that as Principal Investigator, I have ultimate responsibility for the protection of the rights and welfare of human subjects, conduct of the study and the ethical performance of the project.

I agree to comply with Ohio University policies on research and investigation involving human subjects (O.U. Policy # 19.052), as well as with all applicable federal, state and local laws regarding the protection of human subjects in research, including, but not limited to the following:

- The project will be performed by qualified personnel, according to the OU approved protocol.
- No changes will be made in the protocol or consent form until approved by the OU IRB.
- Legally effective informed consent will be obtained from human subjects if applicable, and documentation of informed consent will be retained, in a secure environment, for three years after termination of the project.
- Adverse events will be reported to the OU IRB promptly, and no later than within 5 working days of the occurrence.
- All protocols are approved for a maximum period of one year. Research must stop at the end of that approval period unless the protocol is re-approved for another term.

I further certify that the proposed research is not currently underway and will not begin until approval has been obtained. A signed approval form, on Office of Research Compliance letterhead, communicates IRB approval.

Principal Investigator Signature ___________________________ Date ______

(please print name) ___________________________

Co-Investigator Signature ___________________________ Date ______

(please print name) ___________________________
Faculty Advisor/Sponsor Assurance
By my signature as sponsor on this research application, I certify that the student(s) or
guest investigator is knowledgeable about the regulations and policies governing research
with human subjects and has sufficient training and experience to conduct this particular
study in accord with the approved protocol. In addition:

- I agree to meet with the investigator(s) on a regular basis to monitor study progress.
- Should problems arise during the course of the study, I agree to be available,
  personally, to supervise the investigator in solving them.
- I assure that the investigator will report significant or untoward adverse events to
  the IRB in writing promptly, and within 5 working days of the occurrence.
- If I will be unavailable, as when on sabbatical or vacation, I will arrange for an
  alternate faculty sponsor to assume responsibility during my absence.

I further certify that the proposed research is not currently underway and will not begin
until approval has been obtained. A signed approval form, on Office of Research
Compliance letterhead, communicates IRB approval.

Advisor/Faculty Sponsor Signature ________________________________ Date ______

(please print name) ________________________________

*The faculty advisor/sponsor must be a member of the OU faculty. The faculty member
is considered the responsible party for legal and ethical performance of the project.
Checklist:

X Completed and Signed IRB-1 (this form)
X Appendix A - copies of all consent documents (in 12 pt. Font) including
   ___ Informed Consent to Participate in Research (adult subjects)
   ___ Parental Permission/Informed Consent (parents of subjects who are
        minors or children)
   ___ Assent to Participate in Research (used when subjects are minors or
        children)
X Appendix B - copies of any recruitment tools (advertisements, posters, etc.)
X Appendix C – copies of all instruments (surveys, standardized tests,
   questionnaires, interview topics, etc.).
N/A Appendix D - Copies of debriefing text
X Appendix E - Approval from other IRB, School District, Corporation, etc.
N/A Appendix F - Any additional materials that will assist the Board in completing
   its review
N/A Appendix G – Copies of any IRB approvals
X Appendix H – Copies of Human Subjects Research Training Certificates
   (for all key personnel involved in non-exempt research)

All fields on the form must be completed, regardless of review level. If a field is not
applicable, indicate by inserting n/a. Incomplete forms will result in delayed processing.
Forward this completed form and all attachments to:

   Human Subjects Research
   Office of Research Compliance
   RTEC 117

Questions? Visit the website at www.ohio.edu/research/compliance/ or email
   compliance@ohio.edu
Title of Research: Catalytic Innovations in Appalachia Ohio Health Care: The Storying of Health Care in a Mobile Clinic

Researchers: Karen L. Deardorff

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

EXPLANATION OF STUDY
Purpose of the research: My dissertation will involve observing mobile and fixed clinics conducted by the Community Health Program in the College of Osteopathic Medicine. I will observe the Community Health personnel as they interact between and among themselves and their patients. I will also observe how patients tell their stories of illness, health and healing to health-care providers.

Procedures to be followed: The research procedures of this study include observing the interactions between Community Health Program staff and their patients and conducting in-depth interviews with Community Health Service staff and patients.

Duration of subject’s participation: With your permission, the first stage of the observation will take place during your current interaction with the community health program providers. During this interaction, you will be asked to sign a letter indicating that you are willing to be contacted for a personal interview. The personal interview will take approximately 60-75 minutes and will be held at a location of your choice.

Identification of specific procedures that are experimental: There are no experimental procedures in this project.

Risks and Discomforts
There are no risks involved with your participation in this study.

Benefits
There may be no direct benefits to you, the individual, based on your participation in this study. However, this research project will provide the Community Health Program with information that will assist in programming direction and patient services. In addition, this research project will prove useful to the academic community by creating knowledge about the power of stories in health and healing.
Confidentiality and Records
All interviews will be confidential (your identity will be known only to the researcher) and all interview transcriptions will be anonymous (no one will be able to connect you to your answers). Any contact list containing address, phone numbers, and patient identities will be shredded once interviews have been conducted.

Compensation
There will be no compensation for participants in this study.

Contact Information
If you have any questions regarding this study, please contact Karen Deardorff at deardorf@ohio.edu or by phone at 740-590-1367.

If you have any questions regarding your rights as a research participant, please contact Jo Ellen Sherow, Director of Research Compliance, Ohio University, (740)593-0664.

By signing below, you are agreeing that:
• you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions
• known risks to you have been explained to your satisfaction.
• you understand Ohio University has no policy or plan to pay for any injuries you might receive as a result of participating in this research protocol
• you are 18 years of age or older
• your participation in this research is given voluntarily
• you may change your mind and stop participation at any time without penalty or loss of any benefits to which you may otherwise be entitled.

Signature_________________________________________ Date________
Printed Name__________________________________________

Version Date: [5/18/08]
Ohio University Consent Form (for staff and stakeholders)

Title of Research: Catalytic Innovations in Appalachia Ohio Health Care: The Storying of Health Care in a Mobile Clinic

Researchers: Karen L. Deardorff

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

EXPLANATION OF STUDY
Purpose of the research: My dissertation will involve observing mobile and fixed clinics conducted by the Community Health Program in the College of Osteopathic Medicine. I will observe the Community Health personnel as they interact between and among themselves and their patients. I will also observe how patients tell their stories of illness, health and healing to health-care providers.

Procedures to be followed: The research procedures of this study include observing the interactions between Community Health Program staff and their patients and conducting in-depth interviews with Community Health Service staff and patients.

Duration of subject’s participation: Your participation in this project will occur in three stages. First, I will be observing your interaction with patients (with their and your permission) in the free and mobile clinics during an approximate six-eight month period. Second, either during the observations or immediately following the conclusion of the observations, I will ask for your voluntary participation in a personal interview. This interview will last approximately 60-75 minutes. Third, you may be asked to participate in a member checking meeting with me. This meeting will give you the opportunity to clarify my interpretations or to provide additional information or explanation.

Identification of specific procedures that are experimental: There are no experimental procedures in this project.

Risks and Discomforts
There are no risks involved with your participation in this study.

Benefits
There may be no direct benefits to you, the individual, based on your participation in this study. However, this research project will provide the Community Health Program with
information that will assist in programming direction and patient services. In addition, this research project will prove useful to the academic community by creating knowledge about the power of stories in health and healing.

**Confidentiality and Records**
All interviews will be confidential (your identity will be known only to the researcher) and all interview transcriptions will be anonymous (no one will be able to connect you to your answers). To protect your identity, pseudonyms will be used on all transcripts. Since you may be invited to participate in member checking, a list will be kept which cross references your true identity with your pseudonym. Once the member checking session is complete, this list will be shredded and only the pseudonyms will remain.

**Compensation**
There will be no compensation for participants in this study.

**Contact Information**
If you have any questions regarding this study, please contact Karen Deardorff at deardorf@ohio.edu or by phone at 740-590-1367.

If you have any questions regarding your rights as a research participant, please contact Jo Ellen Sherow, Director of Research Compliance, Ohio University, (740)593-0664.

By signing below, you are agreeing that:

- you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions
- known risks to you have been explained to your satisfaction.
- you understand Ohio University has no policy or plan to pay for any injuries you might receive as a result of participating in this research protocol
- you are 18 years of age or older
- your participation in this research is given voluntarily
- you may change your mind and stop participation at any time without penalty or loss of any benefits to which you may otherwise be entitled.

Signature_________________________________________ Date ___________

Printed Name__________________________________________

Version Date: [5/18/08]
Sample Recruiting Letter for Patients

Dear Community Health Program Patient:

I am currently conducting research to complete my dissertation in the School of Communication Studies at Ohio University. My dissertation topic looks at the communication interactions between and among Community Health Program care providers and patients; specifically, how stories of health and healing are negotiated and treated. My aim is to use this information as a vehicle through which these stories can disrupt and challenge the traditional biomedical models of health care and spark additional dialogue.

The purpose of this letter is to find out if you would be willing to participate in a one-on-one interview with me. The interview will take approximately 60-90 minutes and would be audio taped with your permission. All interviews are confidential and to protect your privacy and identity, pseudonyms will be used in the place of actual names and the actual clinic locations will be altered. The raw data and transcripts will not be provided to any party who might be able to connect you with your specific answers.

If you are willing to be an interview participant, please return this letter before you leave today. Include your contact information (phone number and address) so that I can contact you to establish a date, time, and location for the interview. Again, responses will be kept confidential.

Institutional Review Board regulations require me to obtain written consent from each research participant. A copy of this consent form is attached for your review. I will ask you to sign this consent form and return it to me prior to beginning our interview session.

Please feel free to contact me at 740-590-1367 or at deardorf@ohio.edu with any questions or for additional information.

Sincerely,

Karen Sickels Deardorff
Doctoral Student
Communication Studies
Ohio University

Attachment: Consent Form
APPENDIX C: IRB APPROVAL LETTER

The following research study has been approved by the Institutional Review Board at Ohio University for the period listed below. This review was conducted through an expedited review procedure as defined in the federal regulations as Category(ies):

5 7 0

Project Title: Catalytic Innovations in Appalachia Ohio Health Care: The Storying of Health Care in a Mobile Clinic

Researcher(s): Karen Deardorff

Faculty Advisor (if applicable): Lynn Harter

Department: School of Communication Studies

[Signature]

Jacqueline Legg, M.B.A., Chair
Institutional Review Board

05/19/08 Approval Date

05/18/09 Expiration Date

This approval is valid until expiration date listed above. If you wish to continue beyond expiration date, you must submit a periodic review application and obtain approval prior to continuation.

Adverse events must be reported to the IRB promptly, within 5 working days of the occurrence.

The approval remains in effect provided the study is conducted exactly as described in your application for review. Any additions or modifications to the project must be approved by the IRB (as an amendment) prior to implementation.
APPENDIX D: IRB PERIODIC REVIEW

Ohio University
Office of the Vice President for Research

08X065
Periodic Review

The following research study has been approved by the Institutional Review Board at Ohio University for the period listed below. This review was conducted through an expedited review procedure as defined in the federal regulations as Category(ies):

5 7 0

Project Title: Catalytic Innovations in Appalachia Ohio Health Care: The Storying of Health Care in a Mobile Clinic

Researcher(s): Karen Deardorff

Faculty Advisor (If applicable): Lynn Harter

Department: School of Communication Studies

Jacqueline Legg, M.B.A., Chair
Institutional Review Board

Approval Date
3/22/2010
Expiration Date
3/22/2010

This approval is valid until expiration date listed above. If you wish to continue beyond expiration date, you must submit a periodic review application and obtain approval prior to continuation.

Adverse events must be reported to the IRB promptly, within 5 working days of the occurrence.

The approval remains in effect provided the study is conducted exactly as described in your application for review. Any additions or modifications to the project must be approved by the IRB (as an amendment) prior to implementation.
## APPENDIX E: RESEARCH LOG

<table>
<thead>
<tr>
<th>Day</th>
<th>Times</th>
<th>Hrs</th>
<th>Activities</th>
<th>Audio</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td>1:30-3 pm</td>
<td>1.5</td>
<td>CSP Staff Meeting</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>F</td>
<td>8-10 am</td>
<td>2.0</td>
<td>Advising Meeting</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>W</td>
<td>7:30-11:30 am</td>
<td>4.0</td>
<td>Bus driver physicals</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>3-5:00 pm</td>
<td>2.0</td>
<td>CSP Staff Meeting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>W</td>
<td>6:30-7:30 pm</td>
<td>1.0</td>
<td>Meningococcal Clinic, Parks</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>W</td>
<td>7:30-3 pm</td>
<td>7.5</td>
<td>B&amp;C Clinic, Perry Co.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>St</td>
<td>7:30-3:30 pm</td>
<td>8.0</td>
<td>Health Fair, Trimble High School</td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>8-10 am</td>
<td>2.0</td>
<td>Advising Meeting</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Tu</td>
<td>8:30-10 am</td>
<td>1.5</td>
<td>Advising Meeting</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Th</td>
<td>8-12 pm</td>
<td>4.0</td>
<td>Child Immunization, Parks</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>8:30-10 am</td>
<td>1.5</td>
<td>Advising Meeting</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>M</td>
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<td>1.5</td>
<td>Interview, Janice S.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>12-1 pm</td>
<td>1.5</td>
<td>Perinatal program meeting</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Tu</td>
<td>12-3 pm</td>
<td>3.0</td>
<td>Observation, RiverRose</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Th</td>
<td>10-12:30 am</td>
<td>2.5</td>
<td>Observation, RiverRose</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Tu</td>
<td>1:00-4:30 pm</td>
<td>3.5</td>
<td>Observation, RiverRose</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Th</td>
<td>2-4:30 pm</td>
<td>2.5</td>
<td>Observation, RiverRose</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Th</td>
<td>1:30-3:30 pm</td>
<td>2.0</td>
<td>Observation, RiverRose</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Tu</td>
<td>3:30-4:30 pm</td>
<td>1.0</td>
<td>Staff meeting, RiverRose</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Th</td>
<td>2-4 pm</td>
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<td>Observation, RiverRose</td>
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<td>Yes</td>
</tr>
<tr>
<td>Th</td>
<td>12-1:30 pm</td>
<td>1.5</td>
<td>Observation, RiverRose</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>W</td>
<td>2-4:00 pm</td>
<td>2.0</td>
<td>Interviews, RiverRose</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Tu</td>
<td>2:30-5 pm</td>
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<td>Interviews, Logan</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Th</td>
<td>7:30-11:30 am</td>
<td>4.0</td>
<td>Observations, Stewart Free Clinic</td>
<td>No</td>
<td>Yes</td>
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<tr>
<td>Th</td>
<td>8:30-3:30 pm</td>
<td>7.0</td>
<td>B&amp;C Clinic, Jackson Kroger</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>12:30-4:30 pm</td>
<td>4.0</td>
<td>B&amp;C Clinic, Parks Hall</td>
<td>Kim Clark</td>
<td>Yes</td>
</tr>
<tr>
<td>Th</td>
<td>9-3:30 pm</td>
<td>6.5</td>
<td>Free Clinic, Albany Senior Ctr</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Th</td>
<td>9-4 pm</td>
<td>7.0</td>
<td>Free Clinic, Powell’s, Pomeroy</td>
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<td>Yes</td>
</tr>
<tr>
<td>Th</td>
<td>9-12 pm</td>
<td>3.0</td>
<td>Well child intake</td>
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<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>9-12 pm</td>
<td>3.0</td>
<td>Well Child intake</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Day</td>
<td>Time</td>
<td>Duration</td>
<td>Activity</td>
<td>Yes?</td>
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<td>------</td>
<td>-----</td>
</tr>
<tr>
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<td>Well Child intake</td>
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<td>Yes</td>
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<td>Yes</td>
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<td>Free Clinic, Nelsonville Wesleyan Church</td>
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</tr>
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<td>Th</td>
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<td>3.0</td>
<td>Free Clinic, Stewart</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>M</td>
<td>9-1:30 pm</td>
<td>4.5</td>
<td>Free Clinic, Parks Hall</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Tu</td>
<td>1-4 pm</td>
<td>3.0</td>
<td>Personal Interview</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Tu</td>
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<td>Free Diabetes Clinic, Parks Hall</td>
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<td>HAP Screening, Logan</td>
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<tr>
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<td>Personal Interview</td>
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<td>Personal Interview</td>
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<td>Tu</td>
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<td>Tu</td>
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<td>W</td>
<td>9-4 pm</td>
<td>7.5</td>
<td>B&amp;C, Parks Hall</td>
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<tr>
<td>St</td>
<td>9-12 pm</td>
<td>3.0</td>
<td>HAP, Farmers Market</td>
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<td>Tu</td>
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<td>B&amp;C, Meigs Health Dept.</td>
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<td>Tu</td>
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<td>6.5</td>
<td>B&amp;C, Murray City</td>
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<td>No</td>
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<td>Interview, Mary M</td>
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<td>Interview, Cindy G.</td>
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<td>HAP/Child Immunization, Bishopville</td>
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<td>Tu</td>
<td>9-3:00 pm</td>
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<td>B&amp;C, Vinton Co. Health</td>
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<td>Interview, Greta B.</td>
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<td>W</td>
<td>9-3:00 pm</td>
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<td>B&amp;C, Parks</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Tu</td>
<td>9-3:30 pm</td>
<td>6.5</td>
<td>B&amp;C, Meigs H.D.</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Tu</td>
<td>1-3:30 pm</td>
<td>2.5</td>
<td>CHIP, Parks</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Tu</td>
<td>9-3:30 pm</td>
<td>6.5</td>
<td>B&amp;C, Ross County H.D.</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>S</td>
<td>1-3:00 pm</td>
<td>2.0</td>
<td>Interview, Rose M.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>SU</td>
<td>4-5:30 pm</td>
<td>1.5</td>
<td>Interview, Wendy G.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>F</td>
<td>10-11:30 am</td>
<td>1.5</td>
<td>Interview, Diana K.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Tu</td>
<td>12-1:30 pm</td>
<td>1.5</td>
<td>Advising meeting</td>
<td>No</td>
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</tbody>
</table>
APPENDIX F: INTERVIEW PROTOCOL FOR CHP STAFF

Time of interview: _____________________ Date: _______________________

Place: _______________________________ Pseudonym: __________________

Begin interview by explaining IRB consent form, the purpose of the research, and the anonymity of interviewees.

General Questions
1. Tell me how you became involved with the CHP program.
2. What is your position/title/role in the CHP program?
3. How long have you worked with the program?
4. What did you do prior to your employment with CSP?
5. What is the most difficult aspect of serving in your capacity?
6. What was the impetus for initiating the mobile health and free clinics?
7. What makes the CSP program successful?
8. Which poses the most difficulty for the CSP: funding, space, staffing?
9. What do you see as the biggest barrier(s) you face in providing services to clients?

Narratives
1. Have you ever used stories to help patients understand medical instructions or concepts? If so, what kind of stories do you use? When do you use them?
2. Do you ever use personal stories (i.e. an illness or situation experienced by you or a family member) when talking with a patient?
3. Have you ever made up a story about a personal experience in order to help a patient tell their story or to facilitate medical care?
4. Explain how (if any) the use of personal stories impacts your relationship with the patient.
5. If you have used personal stories, would you share a story and explain why you would use it?
6. Do you encourage your patients to talk about their illnesses or medical concerns? If so, how?
Collaboration/Teamwork
1. Describe how collaboration and teamwork are used?
2. How important is teamwork and collaboration to the success of CHP?
3. Are hierarchies in place, and if so, how do these impact collaboration and teamwork?
4. Describe how duties, support, professional issues, etc., are negotiated.

Patient Education/Intervention
1. What role does intervention play in patient outcomes?
2. What is the biggest health threat facing the rural clients served by CHP?
3. How are patients educated about health-related issues?
4. You recommend that a patient schedule a follow-up appointment with a physician, have further testing or go to the emergency room to seek care. How do you manage not having closure in knowing whether the patient sought additional help?
5. Tell me about a time you feel you were able to make a critical difference in the outcome of a patient’s care and/or life.
6. Tell me about a time you were frustrated because of limitations you faced in helping a patient.
7. If you had to choose a “success story” to explain what the CHP does, what would it be?
8. If you could help me (and others) understand one or two key things about the realities of life for women who seek medical care for themselves and/or their children from the CHP, what would those be?

Space
1. How is space managed in the mobile van and clinic settings?
2. How does space management impact patient confidentiality?
3. How is space negotiated? Hierarchically? Purpose-based?
4. In your opinion, do clients feel more comfortable in a mobile or clinical setting?
5. How does the mainstream medical community perceive the CHP?
6. How do the communities served perceive the CHP?
7. How does CHP differ from mainstream medical care facilities and services?
APPENDIX G: INTERVIEW PROTOCOL FOR CHP PATIENTS

Time of interview: _____________________ Date: _______________________

Place: _______________________________ Pseudonym: __________________

Begin interview by explaining IRB consent form, the purpose of the research, and the anonymity of interviewees.

General Questions
1. Tell me how you became involved with the _____ (mobile health, free clinic, etc.) program. How did you learn about the program?
2. How long have you been using the services provided by the program?
3. Describe a typical visit or interaction with the clinic.
4. How do you believe the program will or has helped you?
5. What is the easiest part of using the program services?
6. What is the most difficult part of using the program services?
7. What is your overall impression about the care you received?
9. What are three words you would use to describe your feelings about needing to use the CHP services?
10. If you could change one thing about how the service is offered, what would that be?

Narratives
1. Describe a time when you feel like medical staff encouraged you to talk about your medical issues or illness. How did that make you feel?
2. Describe a time when you felt medical personnel did not encourage you to explain your medical issues or illness. How did that make you feel?
3. Describe a time when you felt medical personnel took extra time to encourage you to talk about your medical issues. How did that make you feel?
4. Describe your interaction with the medical staff when talking about your illness or medical needs. How important is it to you to tell your story?
5. Have medical personnel ever shared personal stories with you to show they understand your situation? If so, explain.
6. Do you feel more comfortable in a mobile or clinical setting? Explain.
Collaboration/Teamwork
1. Did the staff refer you to other services (Help Me Grow, counseling, follow-up tests, etc.) and, if so, did you use these services?
2. Describe/explain how these services helped you during your illness and/or recovery.

Patient Education/Intervention
1. How (if at all) have the CHP services impacted your life?
2. If you were examined by a nurse practitioner, how comfortable were you talking with someone who was not a physician?
3. Tell me about a time you feel the educational material and assistance you received helped you take better care of yourself.
4. What additional information and/or resources would have aided you during your visit?
5. Did you feel that your privacy was maintained during intake and/or examinations?