

LOW INCOME WOMEN WITH GENITAL HERPES:
RECOGNIZING AND MANAGING THEIR FEAR TRAJECTORY

By

SHIRLEY COUNTRYMAN GORDON

A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL
OF THE UNIVERSITY OF FLORIDA IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

UNIVERSITY OF FLORIDA

1998

Copyright 1998

by

Shirley Countryman Gordon

This dissertation is dedicated to Elaine Ruby King Countryman, my mother and my friend. I thank her for teaching me the value of education for women and for sharing my dreams. The memory of her love and belief in my abilities continue to encourage and support me.

ACKNOWLEDGEMENTS

I would like to thank Dr. Sally Hutchinson, my committee chairperson, for guiding and supporting me throughout this research effort. Without her conceptual sophistication and expertise in the method of grounded theory this study would not have been possible.

I would also like to thank the other members of my committee, Dr. Carolyn Godby, Dr. Jo Snider, Dr. Kathaleen Bloom and Dr. John Sutherland. I appreciate their generous gifts of time, expertise and encouragement. They challenged my ideas and helped to clarify my understanding.

I would especially like to thank the women who were willing to share their very personal experiences of living with genital herpes. I was honored to be the recipient and guardian of such priceless stories.

I would like to thank the members of the institutional review boards (IRBs) who struggled with the concept of qualitative research and who trusted me to have the integrity to pursue research involving the sensitive topic of genital herpes. I appreciate the courage it took to

approve a research study that was outside their view of science.

Finally, I would like to thank my husband, Patrick Gordon, and my son, Sean Gordon, for their unconditional love and support throughout my doctoral education.

TABLE OF CONTENTS

ACKNOWLEDGMENTS		iv
ABSTRACT		ix
CHAPTERS		
I	INTRODUCTION	1
	The Problem	4
	Research Questions/Purpose	6
	Significance to Nursing	6
II	LITERTURE REVIEW	8
	Symbolic Interactionism	8
	Women and Poverty	10
	Women's Sexual Behavior	14
	Genital Herpes	17
	Stigma	20
	Stigma in Health Care Relationships	22
	Chronic Illness	25
	Symptom Awareness	26
	Chronic Illness in Women	29
	Health Care in Chronic Illness	30
	Summary	32
III	METHOD	35
	Grounded Theory	35
	Sample	37
	Human Subjects	39
	Data Collection	43
	Data Analysis	45
	Scientific Integrity	47
IV	THE CRITICAL EVENT OF BEING DIAGNOSED WITH GENITAL HERPES	50
	Socio-Political Context	51
	At Least It's not AIDS	53
	Educational Issues	57

	Diagnostic Issues	60
	Diagnostic Focus	60
	Culturing	61
	Visual Diagnosis	63
	Diagnostic Settings	64
	Stigma Issues	66
	Temporal Issues	68
	Travel and Health Care Issues	73
	Knowing Something Is Wrong	74
	Health Care Provider Response to Diagnosis ...	76
	Low Income Women's Response to Diagnosis	79
	Shock	80
	Denial	81
	Questioning	81
	Anger	83
	Summary	84
V	FEAR: THE BASIC SOCIAL-PSYCHOLOGICAL PROBLEM	86
	Introduction	86
	Fear	87
	Types of Fear	88
	Fear of Pain	89
	Fear of Disclosure	92
	Fear of Passing it On	99
	The Fear Trajectory of Genital Herpes	110
	Factors Mediating Fear Trajectory	112
	Summary	117
VI	MANAGING FEAR: THE BASIC SOCIAL-PSYCHOLOGICAL	
	PROCESS	118
	Introduction	118
	Managing Fear	120
	Phases of Managing Fear	121
	Controlling Information	122
	Controlling Herpes	149
	Regaining Control	166
	Summary	173
VII	SUMMARY AND RECOMMENDATIONS	175
	Recommendations for Practice	176
	Access to Care	176
	Awareness of Fear	177
	Importance of Trust	178
	Recognizing Chronic Nature of Disease ...	179
	Recognizing Individual Variability	180
	Patient Education	180

Study Limitations	181
Sample Representation Problems	181
Research Recommendations	184
HIV+ Women With Genital Herpes	184
Pregnant Women With Genital Herpes	185
Predicting Successful Management	186
Non-Symptomatic Body Awareness	187
Educational Programs	187
APPENDICES	189
A ADVERTISEMENT	189
B PARTICIPANT ABSTRACT	190
C INFORMED CONSENT HRS DISTRICT IX	192
D INTERVIEW GUIDE	194
E DEMOGRAPHIC DATA	196
REFERENCES	198
BIOGRAPHICAL SKETCH	214

Abstract of Dissertation Presented to the Graduate School
of the University of Florida in Partial Fulfillment of the
Requirements for the Degree of Doctor of Philosophy

LOW INCOME WOMEN WITH GENITAL HERPES:
RECOGNIZING AND MANAGING THEIR FEAR TRAJECTORY

By

Shirley Countryman Gordon

December 1998

Chairman: Sally A. Hutchinson

Major Department: Nursing

Every illness tells a story and this study tells the story of low income women with genital herpes. The purpose of this research was to generate a substantive theory about the response of low income women to the critical event of being diagnosed with genital herpes. Data were collected from taped in-depth, interviews from a purposive sample of sixteen (16) low income women who had been diagnosed with genital herpes. Informal interviews were also conducted with five (5) health care providers and several clinic staff members on issues related to stigma and the experience of being diagnosed with genital herpes. All data were analyzed following the ground theory method. Fear emerged as the basic social psychological problem faced by the women participating in this study. Following the critical event

of being diagnosed with genital herpes, fear became a persistent part of their daily lives. Types of fear included fear of pain, fear of disclosure and fear of passing it on. For women in the study, fear was mediated by illness severity, pregnancy, relationship stability and remembering herpes. Participants responded to fear through the process of managing fear. The phases of managing fear included: controlling information, controlling herpes, and regaining control. Women in the study controlled information about genital herpes through selective disclosure, distancing and selectively choosing information. The women used body listening, reading the signs, recognizing triggers and tending to herpes as strategies to control herpes. Women who were able to forgive and move on expressed a feeling of having regained control over the fear in their lives. This substantive theory illustrates how low income women with genital herpes struggle day-to-day to manage their fear trajectory. Awareness of this struggle opens the door for the development of nursing interventions that recognize fear as a pervasive problem for low income women with genital herpes.

CHAPTER 1 INTRODUCTION

Genital herpes simplex virus (GHSV) infection is a worldwide public health concern for which there is no adequate control or treatment (Corey, Adams, Brown, & Holmes, 1983). As an incurable, sexually transmitted disease, it is frequently the first chronic illness of young adults between the ages of 18 and 40 (Corey, Adams, Brown, & Holmes, 1983). Two viral strains (HSV-1 and HSV-2) are believed to be the causative agents in genital herpes infections. HSV-2 is generally associated with genital infections while HSV-1 is thought to be the leading cause of oral-facial infections. However, the two viral strains are not completely site specific (Johnson, Nahmias, Magder, Lee, Brooks, & Snoden, 1990). In an early survey by the CDC, it was estimated that 50% of 20 year olds had antibodies for HSV-I and 25% had antibodies for HSV-2 (reported in Corey, 1993). In more recent studies, prevalence rates of HSV-2 antibodies ranged from 22% to 54% in patients attending STD clinics in western industrialized

countries (Koutsky, et al., 1992; Nahmias, Lee, Beckman-Nahmias, 1990). In developed countries, the highest reported incidence of genital HSV are in Scandinavia and the western coast of the United States (Brown et al, 1991; Skoldenberg, Jeansson, & Wolontis, 1975).

Economic status and gender also play a role in the epidemiology of HSV. Johnson, et al. (1990) reported the presence of HSV-2 in up to 60% of lower socio-economic populations. Interestingly, prevalence rates for HSV-2 are slightly higher for women than men (Corey, 1993). In one study, women ages 21 to 32 experienced a rapid increase in antibody prevalence for both HSV-1 and HSV-2 (Corey, 1993).

Typically, genital herpes appears clinically as painful vesicles that rupture to produce ulcers that then form scabs and heal within 7 to 10 days. Atypical infections also occur and are frequently misdiagnosed. Researchers estimate less than 40% of GHSV cases are accurately diagnosed (Koutsky et al., 1992).

Fever, swollen glands, and flu-like symptoms may accompany primary outbreaks. The lesions recur 88% of the time and recurrences are usually less severe and of shorter duration (Corey, Adams, Brown & Holmes, 1983). Recurrences vary widely and range from one (1) to over twelve (12)

outbreaks per year in healthy adults (Goldberg et al., 1993). Although patients have reported outbreaks associated with sunlight, fever, heat, wind, menstruation, sexual intercourse, masturbation, sleeplessness and stress (Beirman, 1983), the cause of recurrences remains a mystery. The antiviral agent acyclovir is the most effective treatment for easing initial outbreaks and for reducing the number of recurrences (Elion, 1993). However, many people are reluctant to take acyclovir because of uncertainty regarding potential long term effects of the drug and the continued transmission risk from asymptomatic viral shedding (Keller, Jadack, & Mims, 1991).

The virus is transmitted through direct contact with active lesions during sexual intercourse and vaginal deliveries. However, there is evidence to suggest the virus is also transmitted through viral shedding in asymptomatic persons or during the prodromal period before lesions appear (Becker, Stone & Cates, 1986). The possibility of asymptomatic transmission necessitates telling sexual partners about the infection despite control of recurrences with acyclovir.

The Problem

Most GHSV research is medically driven and has focused on physical consequences of genital herpes and drug efficacy studies. As effective treatment and control continues to elude medical scientists, researchers are beginning to focus on the contextual aspects of this chronic disease. Drob (1986) reported the psychosexual aspects of the disease were varied ranging from shame and embarrassment to disabling clinical depression and suicide. Suicidal ideation has been reported in 25% of herpes clients (Warmbrodt, 1993) and described in fictionalized descriptions of the infection (Greenberg, 1992). Swanson and Chenitz (1990) conducted a review of the literature that focused on the psychosocial aspects of GHSV. According to surveys, people with genital herpes believe popular media has played a major role in elevating an otherwise benign chronic illness into a highly stigmatized social illness resulting in profound psychosocial ramifications (Swanson & Chenitz, 1990; Inhorn, 1986; Hillard, Kitchel, Turner, Kerling, & Shank, 1984).

To date, there has been little qualitative research conducted that systematically explores and describes the process of living with genital herpes. What we do know

about living with GHSV is from the perspective of the white middle class (Keller et al., 1991; Swanson & Chenitz, 1993; & Inhorn, 1986).

Our knowledge of the epidemiology of HSV infections suggests that low socioeconomic groups and women of childbearing age are at increased risk for acquiring HSV infections. Meleis (1990) argues that for women living in poverty, health is a complex social matter. Health for low income women is not mastery of their bodies; rather it involves strategizing with environmental and social constraints to achieve freedom from fear. Meleis (1990) defines health for women in this group as relief from worry.

For women living in poverty, fear of acquiring a Sexually Transmitted Disease (STD), like genital herpes, may have a lower priority than fears involving loss of income, housing or a relationship. It can not be assumed persons in all socio-economic groups and both genders experience the disease in the same way. Yet the voices of low income have not been heard. Qualitative studies using methods that explore the personal meaning of GHSV infection for low income women are needed to provide valuable insight.

Research Questions/Purpose

The purpose of this study is to explore and describe the experience of low income women living with genital herpes. Research questions include:

1. What is the basic social psychological problem low income women with genital herpes experience?
2. What is the social psychological process low income women with genital herpes use to solve the problem?
3. What are the social interactional processes for low income women with genital herpes?
4. What are the social structural processes that affect the experience of low income women with genital herpes?
5. What are the contexts in which genital herpes is acquired and experienced?
6. What strategies do low income women use to live with the disease?
7. What are the consequences experienced by low income women living with genital herpes?

Significance to Nursing

While biomedical and survey research have a great deal to offer, understanding of the person in context is equally important. This research extends earlier genital herpes

studies by including the perspective of low income women. The meanings attached to the experience of living with GHSV by low income women may be significantly different from men or other socio-economic groups.

Hearing the stories of what life is like for these women may improve nursing interventions that are both culturally sensitive and personally meaningful. The goal of such interventions is to assist low income women to successfully manage living with genital herpes.

CHAPTER 2 LITERATURE REVIEW

Literature supporting the need for further research into the multi-dimensional aspects of living with GHSV is presented. Topics of review include the theoretical perspective of symbolic interactionism, women and poverty, women's sexual behavior, genital herpes, stigma and chronic illness.

Symbolic Interactionism

Symbolic Interactionism provides a useful theoretical basis from which to study the socially constructed meaning of living with genital herpes. Symbolic interactionism is a socio-psychological theory of social action and assumes that people act and interact on the basis of symbols that have meaning and value for them (Bowers, 1988; Stern, Allen & Moxley, 1982). Persons interact with others and with self. The self is composed of the "I" and the "Me" (Mead, 1934). The Me component is conceptualized as the object of self-reflection while the I component is the reflector. The assumption that each individual is made up of multiple

selves and that the self is constructed through ongoing social interaction is foundational to symbolic interactionism (Mead, 1934; Stryker, 1980).

Symbols (verbal and nonverbal) designate objects in the social world. It is through symbols that individuals try to present a desired picture of themselves and interpret their world and those around them (Stern et al., 1982). Shared symbols allow individuals to interact with others in meaningful and predictable ways. Interaction depends on access to shared symbols. Symbols are continuously redefined as new situations and interpretations of self occur over time within an ever-changing social environment (Swanson & Chenitz, 1993). "Learning the meaning and value of interactional symbols is everyone's lifetime study, and no easy task" (Stern et al., 1982, p.203).

Because GHSV is transmitted within intimate social relationships and is incurable, the infection impacts the interpretation of self and forever changes the social environment. What are the important shared symbols for low income women with genital herpes? How do they interpret genital herpes and it's impact on their lives? What are the complex interpersonal processes involved in living with

the disease? Symbolic interactionism provides a useful theoretical basis to discover what is meaningful for low income women living with genital herpes and how they solve the relevant everyday problems associated with the complex nature of the disease.

Women and Poverty

There is little agreement among scholars on how to define the economic status. Poverty or low income status can be defined as an absolute condition which can be tangibly measured by counting the number of people unable to sustain themselves at some officially agreed upon level (Hobsbawn, 1968).

Using the above definition, many more women than men are living below the poverty line. In 1990, 53.1% of all poor families were headed by women (US Bureau of Census, 1990). The poverty rate for single mother families is six times that of male headed households (French, 1992). Single women over the age of 65 and women raising children alone, make up 70% of all poor people living in the United States (Zopf, 1992). Four groups of women are especially vulnerable to poverty: young single women with dependent children, midlife women who are divorced or widowed, women of color, and aged widows (Thomas, 1994b).

Poverty can also be defined as a relative condition. Townsend (1979) defines poverty as the lack of resources necessary to participate in the activities, customs and diets commonly approved by society. From this view, poverty is seen as a social condition and not merely an economic inequality. Persons living in poverty are isolated from participation in their culture. Consideration of the social consequences of poverty leads to a fuller understanding of the meaning of living in poverty.

Lewis (1966) argues that the poor have a different way of life than the rest of society that constitutes a "lower class culture." Proponents of the "culture of poverty" maintain that poverty is passed from generation to generation because of a variety of psychological disabilities (Banfield, 1970; Lewis, 1966). Characteristics attributed to members of the lower class include: (1) living from moment to moment, (2) belief in a fated future which is beyond one's control, and (3) behavior based on impulse related to a lack of any sense of future (Banfield, 1970).

The above perspective frames poverty, as an individual failing that is difficult to escape despite socioeconomic opportunities or changing structural factors. The culture of poverty fails, however, to explain why women are disproportionately represented among the poor (Thomas, 1994a).

Feminist theorists are beginning to examine women's poverty as a function of the social processes of gender stratification. From a feminist perspective, women are poor because they are working class, because they suffer wage discrimination, because they are African American, Latina, Native American and Asian. Also, because of the social roles that define them as women (Thomas, 1994b), and because they head single parent households.

Several studies have begun to examine the impact of poverty on the lives of women. These studies have shown that poor women experience more frequent, threatening, and uncontrollable life events than the general population (Brown, Bhrolchain & Harris, 1975). They are disproportionately exposed to crime and violence (Belle, 1990; Merry, 1981), illness and death of children (Children's Defense Fund, 1979), and to the imprisonment of husbands (Brown et al., 1975). These acute crises and

events along with chronic life conditions such as inadequate housing, financial uncertainties and discrimination against minority women are potent sources of stress in the lives of poor women (Brown, et al, 1975; Makosky, 1982; Pearlin & Johnson, 1977; Steele et al., 1982).

Given the impact of poverty on women's lives, it is not surprising to find an association between income status and poor mental health (Belle, 1990). Particular interest has been paid to the association between low income and depressive symptoms in women (Kaplan, Roberts, Carmacho, & Coyne, 1987). Hall, Williams and Greenberg (1985) found that depressive symptoms were positively associated with low income, unemployment and single parent status.

Income status has also been shown to be a factor in under-utilization of available health care resources. In a study of prenatal care in low income women, barriers to care included: unemployment, lack of health insurance coverage, multiparity, fear of deportation, fear of discovery of substance abuse, and long waiting times (Zambrana, Dunkel-Schetter, & Scrimshaw, 1991).

Poverty as a gender issue suggests that women and men experience poverty differently. Poverty may play a role in the meaning and consequences of living with genital herpes. In a chronic, communicable illness like genital herpes, income may play a role in the acquisition, transmission and meaning of living with the disease. Financial and situational barriers to care may influence when and if low income women seek medical diagnosis and treatment. A delay in medical diagnosis and treatment may lead to increased transmission of the virus, as well as preventable adverse physiologic and psychological consequences of the disease. It cannot be assumed that all income groups experience genital herpes in the same way. The literature supports income and gender as important variables to consider in exploring the process of living with genital herpes.

Women's Sexual Behavior

In a review of sexually transmitted disease (STD) research, Aral (1994) generalized that social norms and a person's perception of these norms play an important role in affecting sexual behavior. He further generalized sexual norms and ethnicity, income status and gender influence responses to interventions.

A woman's sexual behavior is a factor in the acquisition and later transmission of genital herpes. There is growing consensus among researchers that sexual behavior patterns of women must be understood in the context of their relationships (Cochrane & Mays, 1989; Edwards, 1993; Fullilove, Fullilove, Haynes & Gross, 1990; & Worth, 1989).

In a study of Acquired Immune Deficiency Syndrome (AIDS) risk and risk reduction in black and hispanic/latina women, Mays and Cochran (1988) reported women's sexual behavior is linked to "(a) personal identities, (b) psychological issues, (c) social networks that function as important sources of emotional and tangible support, and (d) social, ethnic or cultural norms" (p.952). The women reported being fearful that risk reduction strategies like demanding the use of condoms would drive men away or lead to violence against them. Because the women in this study believed that men lie or withhold information until a relationship is established, Mays and Cochran (1988) concluded that advising these women to ask about sexual history was counterproductive. "AIDS risk reduction advice asks women to change their behavior as if the behaviors do not have a social context" (Mays & Cochran, 1988, p. 953).

Building on this work, Fullilove et al. (1990) used an adaptation of focus group techniques to explore sexuality with groups of working class and lower-income black women (n=9) and teenage girls (n=19). The participants believed traditional sex roles, permitting sexual freedom for men while denying women that same freedom, are still in operation in the black community. The study suggests that due to an imbalance of power in relationships and the lack of effective communication, women in the black community may not be in control of the use of preventive measures such as condoms and monogamy to prevent the spread of disease. The participants also identified rising male unemployment as a factor contributing to increasing instability in male-female relationships. As the availability of stable men decreases, the positions of power by women in relationships decrease.

Redfern & Hutchinson (1994, 1995) have identified previous history of treatment for a sexually transmitted disease as the best indicator of changing sexual behavior in women. They suggest women learn vulnerability from personal experience rather than from cognitive methods. For women who contract GHSV, the consequences are not

reversible and may negatively influence future social relationships and the health of their unborn children.

Little is known about the impact of genital herpes on sexual behavior. Studies are needed to explore the social complexities of sexual behavior from the women's point of view within the contexts of their everyday lives.

Genital Herpes

Swanson and Chenitz (1993) used a grounded theory approach to describe the experience of young adults' adaptation to living with genital herpes. Their study involved interviewing 70 adults between the ages of 18 and 35. Only 27% of the sample reported an income of \$10,000 or less. Using constant comparative analysis of the interview data, the study's findings indicate that the process of living with genital herpes involves regaining a valued self. The three stages of the process include (1) striving to protect self from devaluation due to stigmatization, (2) renewing sense of self by reaching out and balancing one's life and (3) adopting an information management style that preserves a sense of self.

Stage I, protecting oneself, includes (a) attending: awareness of body and symptoms, and responding to outbreaks and preventive care, (b) reacting: responding to diagnosis

and meaning, (c) seeking explanations and (d) resisting loss: loss of self-esteem, relationships, perfect body image. Stage II, renewing oneself, involved (a) seeking information, (b) managing risks: strategies to increase acceptance while decreasing chances of transmission and (c) balancing one's life: managing symptoms, changing lifestyles, and refocusing one's life. Stage III, preserving oneself, involved revealing, accommodating and avoiding as strategy styles of controlling information about the self. The style adopted enabled respondents to construct and maintain an identity that allowed them to live with herpes over time.

In a later publication, Swanson, Remy, Chenitz, Chastain & Trocki (1993) described the association between illicit drug use and genital herpes. In the sample of 70 participants with genital herpes, all but eight subjects (88.6%) reported having used an illicit drug in the past. Secondary analysis of comparison surveys revealed those with genital herpes were more likely to report ever using an illicit drug and/or using an illicit drug in the past year than subjects in two comparison surveys. It is not clear from this study whether the use of illicit drugs is associated with the acquisition of genital herpes or with

the process of coping with the disease or both. According to the authors, the participants in this study were predominantly white, heterosexual, employed, and college educated.

Using an ethnographic approach, Inhorn (1986) explored "what is it like to be an individual with genital herpes in the mid 1980's". Clinical concerns (recurrence prevention and transmission risks) and problems of "information management" were identified as key life experience categories. Inhorn's vivid descriptions of how individuals managed to live with herpes highlighted the "secret" nature of the infection.

Inhorn found fear of disclosure and rejection played powerful roles in the day-to-day problem of deciding who, when and how to tell others. Fear of disclosure was also supported as a major stressor by Keller et al., (1991), and Swanson and Chenitz (1993).

The studies in this section provide valuable insight into the personal and interpersonal struggles persons with genital herpes face, bringing out the complex contextual nature of this chronic disease. The problems of when, where, and how to disclose you have genital herpes and fear of the negative consequences of disclosure were common

themes despite nearly a decade of media information and the AIDS epidemic.

Studies to date include men and women from predominately the white middle class. The possibility that the process involved in living with genital herpes may differ by gender or socio-economic class should be considered. The persistent nature of these problems and the absence of representation of low income women lends support to further research in this area.

Stigma

In his classic work on stigma, Goffman (1963) described the stigmatized as being socially defined and discredited on the basis of an undesirable attribute that sets the person apart from normal society. The attribute or stigma, reduces the individual "... from a whole and usual person to a tainted, discounted one " (Goffman, 1963, p.3).

Persons who are stigmatized are not accepted by "normal people" and therefore are not treated as equals. Within the context of non-acceptance, shame becomes a central possibility (Goffman, 1963).

Persons who are able to "pass as normal" in social settings are faced with the task of managing information to avoid disclosure which may lead to their being discredited. Because responses to disclosure are uncertain, questions of who, when, where and how to tell others arise (Goffman, 1963). Charmaz (1991) states strategies to create and maintain a desired identity are crucial to persons who have experienced chronic illness and identifies two forms of disclosing: protective disclosure and spontaneous disclosure. Protective disclosure protects the other and self by controlling how, what, when and who to tell about an illness. By controlling the disclosure, or avoiding disclosure, persons are able to claim an identity other than illness. Spontaneous disclosure includes full expression of raw emotion with minimal or no control over the information. People spontaneously disclose when their view of self does not reflect the self-mirrored by the illness (Charmaz, 1991).

Persons with genital herpes are able to "pass as normal" in most social settings. However, because genital herpes is communicable, unpredictable and incurable, moral decisions regarding disclosure come into play. Failure to

disclose genital herpes carries the risk of harming the other even in the absence of clinical symptoms.

Stigma in Health Care Relationships

Stigma effects all interpersonal relationships including those with health care providers. Fear of rejection in the health care setting includes the possibility of physical harm through avoidance.

Tuberculosis is the first disease documented in the literature that describes the hesitancy of nurses to care for patients (Isenberg, 1919; Stewert, 1918). This hesitancy was based on fear of contagion and lack of infection control preparation.

Research involving the perspectives of health care providers early in the AIDS epidemic focused primarily on documentation of fear associated with patient care. In 1987 Blumenfield found that between 25% and 50% of their respondents reported a fear of caring for homosexual males and male prisoners. Half of the nurses in their study reported they would ask for a transfer if they had to care for AIDS patients on a regular basis. Fear extended to the families of the nurses as well. Two-thirds of the nurses had friends or families express concern about their working with AIDS patients.

Breault and Polifroni (1992) more recently reported fear associated with caring for AIDS patients continues to negatively effect health care relationships. Writing from the perspective of nurses, Breault and Polifroni (1992) identified fear, anger, sympathy, self enhancement, fatigue and helplessness as the themes associated with caring for persons with AIDS. Participants in this study did not report they avoided AIDS patients but that their peers did. Of particular interest in this study is the discrediting of persons based on the mode of disease transmission (IV drug and sexual orientation versus blood transfusion) and continuing lifestyles. Distinguishing patients on the basis of moral values (innocent victims versus infection due to immoral acts or lifestyles) first arose in the medical literature in relationship to the syphilis epidemic of the early 1900s (Brandt, 1988).

Discrediting of individuals in health care relationships is not limited to communicable diseases. Stevens and Hall (1988) reported lesbian women are often not comfortable seeking health care. Seventy-nine percent (79%) of the women in their study experienced non-empathetic responses from health care providers after their identity as lesbians was known. They reported being

responded to with embarrassment, shock, invasive personal questions, unfriendliness and fear. Feeling at risk in some health care situations prompted 36% of the participants to terminate an interaction or not return to the provider. One respondent stated "if the environment isn't safe for disclosure, I'm not going to be taken care of. I might even get hurt." (Stevens & Hall, 1988, p.72).

The impact of stigma, fear of being discovered or being treated differently by health care professionals and others, is a common thread in these studies. Stigma associated with lifestyles or disease negatively impacts the lives of individual patients, their families and relationships with health care providers. Lesbians, gays, and persons with AIDS may share a sense of "spoiled identity" (Goffman, 1963) with persons living with genital herpes. Stigmatizing health conditions denies persons full social acceptance. Fear of rejection may alter health care access, health information disclosure and treatment participation. These studies lend support for studying stigmatized attributes, like genital herpes, from the perspective of the individual.

Chronic Illness

Genital herpes is set apart from many STDs by the incurable, life long nature of the illness. It is frequently the first chronic illness in otherwise healthy, young adults. The literature in this section was reviewed for insights into living with a chronic illness and to challenge the assumption that chronic illness impacts people's lives in ways that are similar to acute, short-term illness.

Chronic illness can be described as all impairments or deviations from normal which have one or more of the following characteristics: permanent; leaves residual disability; caused by non-reversible pathological alteration; requires special training of the patient for rehabilitation; and may be expected to require long periods of supervision, observation or care (Mayo, 1956). Given this definition, the incurability of GHSV alone places the disease in the context of a chronic illness.

Arguing that chronic illnesses are qualitatively different from their acute counterparts, Strauss, et al. (1984) identified eight (8) key problems for which patients, their families and friends must develop basic strategies to solve. These problems include: prevention of

medical crises, control of symptoms, carrying out prescribed regimens, prevention of or living with social isolation, adjustment to changes over the course of the disease, attempts at normalizing financial resources, and confronting attendant psychological, marital and familiar problems. The strategies developed to solve these problems require family and organizational arrangements. These arrangements can be quite complex and involve consequences for both the patient and the family. While not strikingly different from social and psychological problems faced by normal people who fall acutely ill, Strauss et al. (1984) believe it is the relative permanence and persistence of these problems that set chronic illness apart, (Strauss et al., 1984).

Symptom Awareness

In describing the complexity of living with MS, arthritis, diabetes, and colitis, Strauss et al. (1984) described the phenomena of paying attention to one's body through symptom awareness as a strategy designed to preserve function and normalize one's lifestyle. Self-management behavior associated with symptom awareness has also been described in adults experiencing asthma and chronic pulmonary disease (Carrieri & Janson-Bjerklie,

1986), and in adults experiencing diabetics (Gonder-Fredrick, Cox, Pennebaker, & Babbitt, 1986; Fox, et al., 1984; Hamera et al., 1988; O'Connell, et al., 1984; Pennebaker et al., 1981; Schorfheide, Eaks, Hamera & Cassemeyer, 1989; Wing, Epstein, Norwalk & Lamarski, 1986). While documenting and describing the phenomena of symptom awareness in chronic illness, the above studies offer little insight into 'how' individuals listen to their bodies.

Using a phenomenological approach, Price (1993) explored the common understandings individuals have about their bodies, the relationships these understandings have with their concerns about health and illness and the impact chronic illness may have on body awareness. The study involved a purposive sample of nine (9) healthy and nine (9) chronically ill (asthma and MS) adults ages 25-55. All of the participants provided statements indicating body awareness and the use of body awareness to direct behavior. One theme common to all groups was the awareness of perceived energy levels--circadian patterns, requirements for sleep and personal limits. However, those with chronic illness had more statements of vigilance, watching for signs and control. The MS group differed from the others

in terms of the degree of daily uncertainty related to predicted energy levels.

The groups reported a difference in the kinds of information they listened to. The healthy group took their body awareness for granted and did not attend or listen to their bodies unless a symptom attracted their attention. The MS group listened to establish physical limits while the asthma group described listening for patterns that would predict symptom exacerbation.

Significant differences also were noted between men and women (Price, 1993). Men tended to objectify their bodies using words that likened their bodies to machines and were concerned with strength and endurance. Women spoke of perceived body shape and the ability to perform specific role functions. The gender difference may have importance for how the meaning of genital herpes is constructed and what one might perceive as losses associated with the illness.

Learning to listen to your body may play an important role in the day-to-day management of living with genital herpes. Learning to recognize the prodromal signs of a recurrence, (tingling, itching) has the potential to enhance the efficacy of acute acyclovir treatment and

decrease the probability of transmission through viral shedding. "Paying attention to one's body" may also be an effective strategy to control the number of outbreaks experienced by an individual through physiologic and psychological stress management.

Chronic Illness in Women

Pacard, Haberman, Woods and Yates (1991) conducted a qualitative study to describe the difficulties or demands associated with chronic illness experiences of women. Women (n=115) experiencing a variety of chronic illnesses were interviewed individually and as a family unit on five (5) occasions at four month intervals. The investigators identified three (3) core constructs/illness demands: direct disease effects, personal disruption and environmental transactions. Direct disease effects, disease-related physical and psychological difficulties, were reported to be the least important illness demands by the women in this study. Contextual experiences of an interpersonal and environmental origin seem to be the most disruptive to women's lives. The findings further support the importance of studying women in context and suggest that women may experience chronic illness in ways that are not consistent with traditional health care models.

Health Care Relationships in Chronic Illness

Research on health care relationships supports the position that there is a problem with consumer satisfaction in health care, particularly in health care for chronic illness (Lau, Williams, Williams, Ware & Brook, (1982) and Pendleton, 1983).

Thorne and Robinson (1989) conducted a multi-phase, qualitative study of health care relationships in chronic illness. Using a grounded theory approach, they generated a substantive theory explaining healthcare relationships from the perspective of patients and their families. Repeated interviews were used to gather data from seventy-seven (77) informants. The analytic process revealed a core variable, reconstructed trust. The theory predicts health care relationships in chronic illness evolve through three stages: naive trust, disenchantment, and guarded alliance. In the final stage, guarded alliance, four (4) patterns of relationships were identified: hero worship, resignation, consumerism, and team playing. It was not clear how the relationship category "resignation" in the phase guarded alliance fit with the core variable reconstructed trust. The researchers suggested the phases

of healthcare relationships in chronic illness might differ from short-term acute illness.

Kaufman (1988) explored boundaries and limits in medicine by looking at the illness experience of patients and their families following a stroke. She described stroke as "a condition in which many accepted boundaries must be reevaluated" (Kaufman, 1988, p. 341). There is no cure for stroke. Kaufman (1988) asserts medical knowledge is not authoritative in the long term care of stroke patients because medicine has little understanding of the lived experiences of surviving a stroke and because much of the patients response to having a stroke is beyond the scope of medical intervention. Kaufman (1988) found individual dilemmas these patients faced were responses to an awareness of the limitations of the health care system to manage and restore their functioning beyond the initial stabilization.

In an examination of the ethical challenges of chronic illness, Jennings, Callahan and Callahan (1988) suggest traditional models of health care delivery fail the chronically ill. The authors support Kaufman's (1988) conclusions that the goal in chronic illness is less defined and, therefore, requires consideration of the lived

experience of the patient and family. Cooper (1990) explores these concepts further in the context of the nurse-patient relationship and challenges practitioners to search for frameworks that are more compatible with the lived reality of chronic illness.

The literature supports the assumption that the experience of chronic illness is qualitatively different from short-term acute illness. This qualitative difference underscores the need for further exploration and description of the experience of chronic illness in general and the experiences of women in particular. The generation of theory to assist in creating new ways for nurses to be in relationship with chronically ill persons is also supported.

Summary

The acute clinical symptom and drug efficacy focus of medically driven research on genital herpes does not adequately describe the multi-faceted dimensions of living with the disease. Genital herpes is a stigmatized, chronic, sexually transmitted disease. As a chronic illness, genital herpes may impact the lives of people differently than an acute, short-term illness. The treatment of genital herpes as acute episodes by health

care providers denies the chronic nature of the disease and may leave patients unprepared to successfully manage their lives.

The stigma associated with the disease may negatively effect the everyday lives of patients and their families and the socially constructed meaning of living with the disease. Deciding whom, when and how to tell others you have genital herpes (including health care providers) may be influenced by the stigma associated with genital herpes and the sexual role of the individual.

Despite being at increased risk for STDs in general, the voices of low income women have been silent in the GHSV research. The social context and meaning of sexual behaviors in this group are poorly understood (Aral, 1990). Poverty significantly impacts the context in which women must learn to live with the disease. The participants in earlier genital herpes studies were predominantly from the white middle class and did not focus on women (Swanson & Chenitz, 1993; Inhorn, 1986).

Qualitative research describing the social meaning low income women attach to experiencing genital herpes is needed to enrich our understanding of the disease. The generation of theory describing behavior patterns that are

relevant and problematic to low income women may lead to nursing interventions that are both culturally sensitive and personally meaningful. The goal of such interventions is to assist low income women to successfully manage living with genital herpes.

CHAPTER 3 METHOD

Grounded Theory

The review of the literature demonstrates a paucity of qualitative research exploring GHSV as a chronic, sexually transmitted disease. As a result, little is known about the impact of the disease on patients and their relationships with others.

People who share a common circumstance like, living with genital herpes, experience shared meanings and behaviors. Due to the sensitive nature of the disease, these experiences may not be articulated. Working within a Symbolic Interaction framework, grounded theory offers an ideal method to discover how low income women with genital herpes solve the relevant everyday problems associated with the complex nature of this disease.

"The grounded theory approach is a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a

phenomenon" (Strauss & Corbin, 1990, p.24). Grounded theory is particularly useful "where existing research does not adequately reflect the perspective of the subjects" (Bowers, 1988, p.53). Based on a discovery model of theory development, the purpose of grounded theory method is to generate theory around a core variable or process that accounts for a pattern of behavior which is "relevant and problematic for those involved" (Glaser, 1978, p. 93). "The researcher aims at capturing all of the variation in the phenomenon under study and examining conditions under which the phenomena occurs, as well as conditions under which it varies" (Chenitz & Swanson, 1986, p.41.). Theories derived using the grounded theory method are grounded in empirical data as opposed to theory that is logically derived.

In grounded theory, the researcher works "within a matrix where several processes go on at once" (Stern, Allen & Moxley, 1982, p.205). The grounded theory method combines theory building techniques that call for the continual redesigning of data analysis, with careful coding and a data comparison method (Stern et. al., 1982). The method assures that the emerging theory is grounded in the

study data rather than being forcibly fit into an existing grand theory (Stern et. al., 1982).

Sample

Qualitative studies frequently utilize purposive sampling strategies to recruit spokespersons who are willing, articulate and helpful in generating the quality of data required for meaningful analysis (Stevens & Hall, 1988). Sampling was initially directed by the research questions and guided throughout the project by a strategy called theoretical sampling (Chenitz & Swanson, 1986). The goal in theoretical sampling was to assure dense data that allowed the researcher to illuminate and expand theoretical constructs (Hutchinson, 1993). Theoretical sampling involved sampling events or incidents on the basis of concepts that were relevant to the emerging theory (Strauss & Corbin, 1990). Concepts were considered relevant if they were repeatedly present or noticeably absent when comparing incident to incident (Strauss & Corbin, 1990).

Theoretical sampling was cumulative and increased in depth of focus as the research progressed (Strauss & Corbin, 1990). Initially the researcher generated as many concepts or categories as possible. Sampling later focused

on specific areas to develop, densify and saturate selected categories (Strauss & Corbin, 1990).

In this study, the purposive sample was solicited from organizations and private practitioners that provided health care for low income women. These organizations included a Planned Parenthood clinic, high risk pregnancy clinic, two private practitioners and two public health units (Public Health Unit A and B). Participants were recruited through "known others" such as physicians, nurse practitioners and clinic staff. Advertisements describing the study were posted in appropriate facilities (clinics, physician offices etc.) encouraging interested persons to contact the investigator or to speak with their care provider about participating in the study (See appendix A). Problems associated recruiting participants through advertising are discussed in chapter seven under study limitations.

The sample for this study consisted of 16 women that met the following criteria: (1) English speaking, (2) 18 years of age or older, (3) low income status; earning 10,000 dollars a year or less and/or eligible for public support and (4) diagnosis of genital herpes. A total of 22 women in two counties were referred to the study.

Interview transcripts for 16 women were used in the data analysis. Of the six women not included in the study, two women contacted the researcher in response to advertising and chose not to participate in the study. The four remaining referrals could not be reached or failed to show up for scheduled interviews.

The 16 women participating in the study were all of childbearing age between the ages of 18 and 35. The average age of the participants was 26.7 years. The participants had been diagnosed with genital herpes for an average of 2.7 years, with a range of initial diagnosis to 5 years. Of the participants, 34% were Black, 49% were European-American, 16% were Hispanic and 1% identified themselves as other. The majority of the participants (73%) were single. The average number of children was 2 with a range of zero to four children. The number of reported sexual partners in the past year ranged from zero to two partners. Sixty-three percent of the participants reported one sexual partner in the past year.

Human Subjects

Participants had the study explained to them before being asked to consent to the interview. Genital herpes can be classified as a sensitive topic because it is a STD

and involves discussing the private sphere of sexual behavior (Lee & Renzetti, 1993). Sensitive topics may involve psychological costs to the participants such as shame, guilt or embarrassment (Lee & Renzetti, 1993). However, the sensitivity of a particular topic is emergent. In other words, sensitivity is not inherent in a topic but emerges out of the relationship between the topic and the social context within which the research is conducted (Lee & Renzetti, 1993). What is sensitive to one group of people may not be sensitive to another.

Genital herpes is a stigmatizing communicable disease. Persons who disclose they have the infection risk being socially discredited. The potentially sensitive nature of the disease required an increased awareness of any potential risks of the research and increased diligence in the protection of human subjects. Participants were kept informed of their vulnerability to potential dangers as the direction of the research became increasingly focused. Ramos (1989) and Sieber (1993) describe this process of consensual decision-making in the literature. The researcher remained open to perceiving risk factors from the perspective of the participants (Seiber, 1993).

At the time of the interview, the researcher explained that the participant was being asked to volunteer to participate in a research study to explore what it is like for women to live with genital herpes. The participants were informed that the interview was expected to take about an hour and that they were free to withdraw from the study at any time without effecting their health care. In addition, verbal consent to audio tape the interview was obtained.

Participants were informed that they might benefit directly from sharing their experiences and that the information gained may be helpful to other women with genital herpes. Participants were not paid to participate in the study. There were no expected risks to the participants. However, participants were informed that while some women found sharing their experience helpful, other women may become upset. Participants were told they would be referred to their regular health care provider for assistance if they became upset and wanted to talk with someone.

Participants were provided with a copy of a participant abstract (see appendix B). Or informed consent (see appendix C). Only the State of Florida Review Council

for Human Subjects required a signed informed consent. Recruitment problems related to asking low income women with genital herpes to sign an informed consent are discussed in chapter seven. The informed consent or participant abstract was read to phone interview participants. Phone participants recruited through public health units were informed that a colleague would be listening in on the consent process to ensure their rights were protected. Colleagues signed the informed consent form to record they had witnessed the verbal consent. All phone participants were asked if they would like a copy of the informed consent or participants abstract mailed to them. None of the phone participants requested a mailed copy. All participants consented to the having the interview taped. Anonymity of the participants was protected. No names were attached to the interview tapes or transcripts. Each participant was assigned a code number that was used on all tapes and transcripts. The list of participant names and code numbers are available only to the researcher. Only the researcher, her faculty advisor and research group saw the transcripts. Audio-tapes were magnetically erased following transcription. Transcripts were kept in a locked file cabinet or in the

possession of the researcher. Transcripts were destroyed upon the completion of the research.

Data Collection

Following an initial telephone contact, a copy of the study abstract, participant abstract and IRB approval letter was sent to interested physicians, nurse practitioners, and clinic administrators. A return phone call was made to verify receipt of study materials and to schedule an opportunity to meet and discuss the study. When possible, I met with these gatekeepers to familiarize them with the study and to clarify any questions they might have about the study. The gatekeepers were asked to recommend and contact participants who met the sample criteria

Interview times and places were scheduled with each woman who consented to participate in the study. Interviews were conducted in a private, comfortable, convenience place for study participants and lasted approximately 60 to 90 minutes.

Data were collected using a formal semi-structured interview process. An interview guide was used to facilitate the interview (See appendix D). Content areas of the interview guide were intended to discover meanings

attached to GHSV, perceived impact on relationships, as well as the effect on daily life and the future. While face to face interviews were preferred, some participants were more comfortable speaking about their experiences over the telephone. Aral (1994) reported "self administered questionnaires and telephone interviews seem to provide more complete data" in STD research (p.560). Three initial interviews and all follow up interviews were conducted by telephone. Follow up interviews were conducted with permission of the participants to clarify data or seek additional information. All participants consented to participate in follow-up interviews.

Demographic information such as age, income, race, education, occupation, marital status, number of children, number of people living in the household, recurrency triggers, drug use history, were obtained for descriptive purposes (See appendix E).

Other relevant data sources were selected to expand and substantiate the database. Examples included documents such as printed patient education material, Center for Disease Control Guidelines for Treating STD's, TV coverage of medication advertisements, and informal interviews with five (5) nurse practitioners (ARNP's) and several clinic

staff members. The ARNP's were selected using a purposive sampling technique. The sample included representatives from the types of recruiting locations utilized in the study and varying levels of clinical experience with low income women. The ARNP's ranged in age from 36 to 56 years and were all women. Twenty percent of the ARNP's were black and eighty percent were white. Years of clinical experience working with low income populations ranged from one to twenty three years.

Data Analysis

Grounded theorists assume that groups share a specific basic social-psychological problem (BSPP) that is solved by means of basic social-psychological processes (BSP) (Hutchinson, 1993). Data analysis was directed toward discovering the BSPP and the BSP that emerged within the context of the study (Hutchinson, 1993).

Analysis of the interview data used the constant comparative method of Grounded Theory. In this method, data analysis took place simultaneously with data collection. By comparing and coding the data as it is collected, the researcher created increasingly abstract theoretical connections (Glaser, 1978).

Using the constant comparative method, tape-recorded interviews were transcribed and progressively coded into three levels: substantive codes, categories and theoretical constructs (Hutchinson, 1993). Using a line-by-line approach, substantive codes conceptualized the action in the setting. Incidents were compared to incidents to insure similar phenomena were given similar names.

Substantive codes were clustered or grouped into categories that seem to pertain to the same phenomenon. The third level of coding required the researcher to conceptualize the relationships between the three code levels. "Grounded in the substantive and categorical codes, theoretical constructs gave the theory integrative scope, a new perspective and theoretical meaning" (Glaser, 1978, p.72).

An ongoing record of theory development was maintained through a process of memoing. Memoing was used to "capture" the researcher's feelings and decision-making processes. Initially memos were used to record decisions about sampling, shifts in the focus of research questions, and early categories. Subsequent memos focused on comparing the relationships among categories and how relationships varied under different circumstances. Memos

became progressively more abstract and integrated as data analysis progressed.

Scientific Integrity.

The main limitation in qualitative research is researcher bias. Edwards (1993) argues that the research process involves "double sensitivity" due to the characteristics and biases of the researcher and the participants' perception of the researcher and the research. Plummer (1983) says it is difficult for subjects to grasp what is required of them, particularly in response to open ended interviews where they are expected to lead rather than to merely respond to questions. Unfamiliarity with the interview process due to lower educational levels and fewer opportunities to interact with researchers may be particularly significant in low income populations.

Because interviewing is an interactive process, racial, class, and gender differences and similarities can influence not only willingness to participate in the interview process but the quality of the interview data as well. Strategies used to overcome or balance potential difficulties of a white female researcher interviewing racially mixed, low income women in this study included: use of (1) open interview structure to counter implicit

racism on the part of the researcher (Griffin, 1987), (2) use of key informants to clarify conceptual meanings and assist in interpreting culturally derived behavior, and (3) concluding interviews with a question exploring how participants felt about taking part in the study to provide insight into the unexpected ways social characteristics may have influenced the interview process (Edwards, 1993). Researcher bias was also examined in research seminar groups and in consultation with the committee chair.

In qualitative studies, the non-numerical nature of the data necessitates constant validation of meaning and communication with informants (Leininger, 1985). Credibility of the research findings were enhanced through the use of strategies such as: (1) in process and terminal member checks, (2) searching for alternative hypotheses and negative case studies (Hutchinson, 1993), and (3) triangulation through the use of multiple data sources (Denzin, 1978).

The substantive theory generated is limited to the low income women interviewed in this study. However, the basic social process identified may be applicable to low income women or women in general (Hutchinson, 1993). Thick descriptions of the context of the study were provided to

allow practitioners to evaluate the possibility of transferring the findings to specific patient populations and practice settings. Lincoln & Guba (1985) advise carrying out a "small verifying study" whenever transferring the results of qualitative studies.

Dependability was enhanced through the use of the constant comparative method of data analysis in grounded theory. The researcher returned to informants to ask more focused questions as data analysis proceeded. The data were constantly compared and contrasted throughout each phase of the study.

In qualitative studies, the researcher is thought of as the data collection instrument. Therefore, the researchers' feelings and experience were analyzed as an integral part of the study (Edwards, 1993). A reflexive journal was maintained throughout the study to record information about self and method (Lincoln & Guba, 1985). Reflexive journals are introspective diaries that explore the researchers thought processes, philosophical positions and bases of decisions about the inquiry (Lincoln & Guba, 1985). Because the reflexive journal provides information about the human instrument, it served as a means of establishing overall trustworthiness of the study.

CHAPTER 4
THE CRITICAL EVENT OF BEING DIAGNOSED WITH GENITAL HERPES.

The principles of symbolic Interactionism and feminist research provide the perspective that shapes this chapter. Symbolic interactionism is a social psychological theory of social interaction and assumes that people act and interact on the basis of symbols that have meaning and value for them (Bowers, 1988; Stern, Allen & Moxley, 1982). Feminist research, by design and execution, prioritizes womens experiences, ideas and needs; samples women from a variety of ethnic/racial backgrounds and a range of socioeconomic circumstances; draws on women's own interpretations of their experiences; and raises consciousness about women's daily struggles, urging change in the interest of the women studied (Hall, 1994; Hall & Stevens, 1991; Collins, 1989; Cook & Fonow, 1986; Duffy & Hedin, 1988; Jagger; 1988; Stanly & Wise, 1983).

To date, in the dialogue surrounding the day-to-day impact of genital herpes on the lives of women, the voices

of low income women have been silent. This chapter looks at the critical event of being diagnosed with genital herpes from the perspective of low income women.

Socio-Political Context

In 1980 genital herpes became the disease of the year. Ironically, a Federal Drug Administration announcement approving Acyclovir as the first anti-viral drug available to treat Genital Herpes Simplex Virus (GHSV) served as the news event that triggered sensational media coverage of the disease (Flannery, 1983).

Time Magazine (Herpes, 1980) began the media coverage of genital herpes with an article entitled Herpes: The New Sexual Leprosy. Sensational titles such as The Terrible Curse of Herpes (1982), The New Scarlet Letter (1982), and Herpes: The Scourge of the Sexual Revolution (1983) followed. Journalistic use of metaphors such as "leprosy", "curse" and "scourge" were damaging because they exaggerated the severity of the disease and painted a picture that affected public perception.

Genital herpes is not talked about openly. Therefore, many people's experience with GHSV is limited to information received from the media. What had been considered by Healthcare Providers (HCPs) to be a mild

infection, which if kept clean would heal spontaneously (Rae, 1985), is depicted in the media as a social death sentence. A biased representation of herpes in the media contributes to a distorted public perception of the disease. "If one's experiences are biased, one's perceptions are likely to be inaccurate" (Slovic, et al., 1982, p.467). Media attention to genital herpes began to wane as another, more deadly STD took center stage. In 1983, media coverage of AIDS began. With its' deadly outcomes and uncertain transmission modes, GHSV seemed mild in comparison. Today, AIDS continues to dominate the media as GHSV has been reframed by the medical community as a benign chronic illness for otherwise healthy adults.

Unfortunately, the stigma fanned by media coverage of the disease in the 1980's continues. Stigma is a social construction that affects the life experiences of individuals infected with GHSV. Although all illness in American society is negatively valued (Parsons, 1951), herpes is particularly stigmatized because it is a chronic, contagious and sexually transmitted disease. Moralistic judgments blaming the individual are common in response to sexually transmitted diseases (Freidson, 1965). One health care provider responded:

You are not allowed to pass judgment on how people get AIDS--it's just not politically correct--but herpes is another story.

Women remain terrified that a diagnosis of genital herpes will make them social outcasts and destroy any possibility of leading a normal life.

At Least It's Not AIDS

In the shadow of AIDS, health care providers frequently minimize the struggle low income women face as they live day-to-day with genital herpes. To minimize is to represent as having the least degree of importance or value (Morris, 1981). In a survey conducted by the American Social Health Association (A.S.H.A.), participants stated that the suffering, anguish, and personal tragedy resulting from GHSV had either been unrecognized or understated by their health care providers (Helping the Medical Community, 1996). Low income women continue to encounter health care providers who minimize the impact of GHSV on their lives.

Genital herpes is frequently minimized by comparing it to AIDS. The phrase "at least it's not AIDS" is used to make the impact of GHSV on the lives of low income women seem minimal in comparison. One woman said:

When you hear that you have something like that, that's something that you hear about through the years when you are going to school, you know, stuff in health class. You hear all bad things about it so then you find out you're diagnosed with it, it's kinda like, you know, I guess my doctor told me, let's look at it this way, at least you don't have AIDS, you know because you can die from [AIDS], you can get very sick from it and this you cannot.

An ARNP acknowledged:

It's really not such a big deal. We can't do anything about it and it doesn't kill them. They just have to learn to deal with it. I almost wish it [herpes lesions] would hang around a little bit longer - they [low income women] might take it more seriously.

Others factors contributing to the minimization of herpes by health care providers include its' non-reportable status; lack of effective treatment or cure; self limiting characteristic; and low morbidity and mortality rate in healthy adults. In addition, a general lack of understanding of the day-to-day struggle of living with the disease exists.

In most states genital herpes is a non-reportable disease. Therefore, most Public Health Units do not track the incidence of herpes in the community or conduct contact tracing. They have no interest in the disease other than to diagnosis and treat presenting cases. There are no special programs, no funding, no support groups within the public health unit for people with genital herpes. Genital

herpes is not looked at in evaluating the overall health of a community. Classification of genital herpes as a non-reportable disease contributes to its minimization. One Unit manager said:

Herpes is not reportable--so it's not a problem for us. I would guess it is a problem for them [women in the study].

The goal of the public health unit STD clinic is to diagnose and treat reportable STDs as a strategy to control the spread of disease within the community. HCPs in this setting feel an obligation to protect the health of the public. Their overriding concern is for the public in general, not directly for the individual presenting with an STD.

I think our focus here [on] treatment of sexually transmitted diseases prevents the spread. And its not easy to say to somebody that you know you have a sexually transmitted disease and you should avoid spreading it to another person if possible, but that is our goal here.

[CDC] so heavily stresses that either one of these diseases [HPV and herpes] have no treatment and so the only way you can reduce the incidents is to reduce the spread of them by contact.

The self-limiting nature of herpetic outbreaks also contributes to minimization of the disease by HCPs. While primary infections may last 2-3 weeks, recurrent outbreaks

resolve themselves in 7-10 days without treatment. If anti-viral medications are started at the first signs of an outbreak, the duration may be limited to 3-4 days. Complications in healthy adults, such as secondary bacterial infection, are rare. Because herpetic lesions clear with or without treatment, it is easy for HCPs to categorize the infection medically as a minor inconvenience. An ARNP in private practice describes her understanding of genital herpes in the following manner.

Herpes is self-limiting. I would consider herpes one of the more minor issues in regards to sexually transmitted diseases and vaginal complaints. You know, I'm usually looking for more infectious processes or more life threatening kinds of things.

Many HCPs do not believe they have a role in disease management unless the woman is currently experiencing an acute exacerbation or reactivation of the GHSV. HCPs therefore, have a tendency to focus on acute exacerbation of the virus and ignore the chronic nature of the disease. Genital herpes is seen as being problematic by HCPs only during outbreaks. This perspective alters risk benefit assessments in regard to the use of anti-viral medications. One practitioner described being hesitant to prescribe anti-viral medications to low income women of childbearing age. Her hesitancy was based on an assessment of the

limited benefit of medication and the risk involved in prescribing a drug that was not approved for use during pregnancy.

There is nothing I can do for them [low income women] unless they are having an outbreak and even then there are considerations like whether or not they are using a reliable form of birth control that influence my willingness to give them medication.

Because the voices of low income women have been silent in existing research studies; health care providers do not understand the complexity of living with the disease. Genital herpes is a chronic illness. As a chronic illness, genital herpes impacts the daily lives of low income women. Its influence is not limited to the period of time individuals experience acute exacerbations or outbreaks. Lack of understanding makes it difficult to have a conscious awareness of the genuine problems faced by low income women as they struggle to live with genital herpes. Limited knowledge of the experience of living with genital herpes makes it easier to minimize the consequences of the disease for this group of women.

Educational Issues

Concern for the health of the public is reflected in treatment protocols and information provided to women diagnosed with GHSV. Because the goal is to prevent the

spread of STDs in the community, information provided to women diagnosed with GHSV is based on Center for Disease Control (CDC) guidelines and community control principles.

The health care industry has a tendency to back up any teaching with printed materials (Meaningful Care, 1998). This is particularly true today as managed care reduces the amount of time available for teaching. Availability of patient education materials varies from setting to setting. At Public Health Unit A, genital herpes information is not included in the education display located in the waiting room. Planned Parenthood and private practitioners providing services to pregnant women place the materials openly in the waiting room. Other providers keep the materials in a conference room or office and provide them when appropriate.

The materials are written at a level beyond the reading skills of many low income women. Gordon & Sherrod (1996) reported commercial and generic GHSV instructions were written between the 8th and 10th grade reading levels. In addition to high reading levels, instructions frequently included few pictures and small print. In most settings, materials were available in English and Spanish only. In

response to the impact of reading level on comprehension, one ARNP commented:

I think that after they have been diagnosed someplace else, say they went to clinic, they [health providers] say "Hey you have herpes, where's your boyfriend, use a condom, here's a pamphlet". And they don't read it and if they do, they don't understand.

Educational materials address the medical facts of genital herpes: it's a virus; there is no cure; symptoms return; time between outbreaks is unpredictable; stress brings on outbreaks; and it is passed through intercourse, oral sex or during the birth process. The medical facts set the stage for discussing transmission control.

The main focus of the educational materials is on preventing transmission. The text of the materials reads like a warning--you will pass the virus unless you: avoid sexual contact when blisters are present; abstain for one (1) week after blisters resolve; and discuss your disease with your OB doctor so he/she can protect your baby.

What is notably absent from the materials is meaningful information on how to live with the disease. Psychological issues such as how to tell a partner you have herpes, strategies to manage stress, shame, guilt, condom use, pain, medication use, how to recognize prodromal signs and contact numbers for support groups are not discussed.

Failure to address these issues supports the concern for transmission over individual health and denies the chronic nature of the disease.

Diagnostic Issues

Diagnostic Focus

The focus on diagnosis and treatment of reportable STDs can narrow diagnostic vision and contribute to misdiagnosis. Despite evidence to support that genital herpes is the most frequent cause of genital ulcers in industrialized countries (Schmid, 1990), herpes is not always the first diagnosis to be ruled out or even considered. An ARNP in private practice said:

Genital herpes, per say, is not one of the things that I would be looking for necessarily, and the reason for that is just basically there is not a medical intervention to be done at that point in time, so I think it is frustrating from a medical perspective to find someone in that situation.

Not looking for herpes can lead to missing the diagnosis. An ARNP working in a high-risk pregnancy clinic reported:

Umm, yesterday a little girl came in, her boyfriend has a sore, and he finally went to a clinic and the clinic said he had chlamydia. And then, they said, 'Oh, I think its syphilis'. And then low and behold it turned out to be herpes. And now she is in here terrified.

Culturing

Over and under diagnosis of GHSV occurs. It is estimated that 50% of women who have antibodies to HSV type 2 have been misdiagnosed or are unaware they have ever been infected ("Guidelines for Women's", 1996). One factor contributing to misdiagnosis is failure to routinely culture genital ulcers.

The American College of Obstetrician and Gynecologist Guidelines recommends confirmatory cultures of GHSV ("Guidelines for Women's", 1996). This recommendation is based upon the frequency of misdiagnosis and on the significant social implications of GHSV. Despite this recommendation, the decision whether or not to culture for genital herpes varies by institution and individual practitioner and is influenced by political, social and economic concerns as well as personal beliefs of individual practitioners.

Low income women do not always have access to the same services as other women. Institutions providing services to low income women frequently do not routinely culture because herpes cultures are expensive and medical intervention for the disease is limited. An ARNP at Public Health Unit A expressed frustration with this policy.

One of my biggest frustrations as a provider is that we don't do cultures here. I think I see a lot of denial where they [low income women] don't want to have herpes and they are just looking for something else that they want it to be and I think it would be really nice to say, 'lets' do a culture' and then we will have some visible proof for a person that you know this is what you have and that was particularly true in the situation where the woman was assaulted. Where she just didn't want to believe that this had happened and it would have been very beneficial to me as a provider to say 'here is the evidence'. Instead we have to go here on symptoms and visually looking to see the characteristic source of lesions, and I would prefer to have something that you could define more clearly.

When asked about the reason for not culturing, she answered:

It's expensive and we are not going to treat the initial outbreak anyway. If it recurs that would confirm it's herpes and we might treat it at that point in time.

At Public Health Unit B the policy on culturing was reported to be quite different. The decision whether or not to culture was left to individual practitioners. In this setting, one practitioner described her practice of delaying definitive diagnosis until culture reports could confirm GHSV.

If someone has a lesion, I would culture it. If it looked like herpes or even if it didn't, I would culture it and wait for the results to come back. If I think it is a presumptive diagnosis, I just tell the person it's one of the many possibilities it could be.

An ARNP in private practice described struggling with the decision to culture or not culture low income women on the bases of economics and limited medical intervention.

Diagnosing is often just by visual inspection, it's rarely by culture, and I think that enters again into the economic issue. Is it worth doing an expensive clinical test when there is not much I can do about it?

Visual diagnosis

In the absence of cultures, HCPs must rely on visual signs and physical symptoms to make a diagnosis of genital herpes. Typically, herpetic lesions appear as painful clusters of vesicles that rupture to produce ulcers that then form scabs. The virus may also appear as a sensitive reddened area in the genital region. Atypical lesions complicate the visual diagnosis of genital herpes. Even experienced examiners may over or under diagnose GHSV (Sexually Transmitted Diseases, 1996).

Gender also plays a role in the misdiagnosis of genital herpes. Visual diagnosis of GHSV is thought to be more problematic in women than in men. Women can have herpes infections of the cervix, vagina and vulva. While infections of the lower genital tract are the most common (Sexually Transmitted Diseases, 1996), the hiddenness of the internal genitalia of women plays a role in diagnosis or

misdiagnosis of GHSV. Folk beliefs about the human body support that "women's genitalia are hidden, dangerous, and unknown, harboring the virus ready to attack, about which women are unaware, whereas men's genitalia are open, visible and known" (Pliskin, 1995 p. 487). In this context, women are seen as being sexually more dangerous than men.

So, I think it's very difficult to tell if that's an actual initial outbreak or not. Especially with women because you don't see it as easily. On men, it is much more easy to visualize the lesions

It's always easier to visualize what is external than what is internal. It has been my experience that when I try to do an internal exam with a speculum, that if there are internal lesions the patient will have a real exaggerated response. Even more so than patients that have pelvic inflammatory disease, because with those kind of patients you see cervical motion tenderness whereas patients with vaginal herpes are really, really in excruciating pain just from the manipulation. So yes, it is more difficult to identify them visually but it's a pretty clear presentation on a vaginal exam if they have already broken the surface. When they present with only a reddening of the area cause it hasn't really ulcerated you'll still see pain, but it is much more difficult then to diagnose. You wonder what else might be there.

Diagnostic Settings

Income status influences where and how women seek medical attention when they know something is wrong. The women in this study sought diagnosis and treatment in a variety of settings that would accept Medicaid, had sliding

payment scales or didn't ask for money up front. The settings identified in the study included emergency rooms, nurse practitioners in private practice, planned parenthood, a high risk pregnancy clinic and two public health unit STD clinics (PHU A and PHU B)

The experience of being diagnosed with GHSV varied depending on the setting and individual practitioner. The most frequently used setting in this study was a public health STD clinic. PHU A clinic is located on the second floor of the main public health unit building for a large county in South Florida. The clinic is open Monday through Friday, excluding holidays, from 7:30 am until 12:00 PM. The busiest days of the week are Mondays and any day following a holiday.

Patients are seen at the STD clinic in three capacities: referred, contacts, and walk-ins. Referred patients have received a positive lab report for a reportable STD and are referred to the health department for treatment and follow up. Contacts are people who have been notified by the health unit that it has been reported they have had sexual contact with a person who tested positive for a reportable STD. Contacts are seen for evaluation and treatment if needed.

The participants in this study that were diagnosed with genital herpes at the public STD clinic were seen as walk-ins. They came to the STD clinic because they knew there was something wrong "down there" and that they could be seen that day for diagnosis and treatment.

The system works on a first come first served basis. Patients walk up to a registration window that opens onto a large waiting room. Both the registration window and waiting room are visible from the elevator door. Registration takes about 15 minutes and involves providing basic information such as name, address and contact numbers.

Patients do not discuss their complaints or symptoms with the registration clerk. After registering, patients receive a number to protect their confidentiality. It was well known in the community that walk-ins had to appear early to "get a number" if you wanted to be seen.

Stigma Issues

After receiving a number, patients sit in the waiting room until their number is called. It is clear everyone sitting in the STD waiting room is there to be seen for something related to a sexually transmitted disease or is accompanying a person waiting to be seen. The risk of

being seen associated with STD clinics was expressed by an ARNP working in a high-risk pregnancy clinic.

Sometimes you have to go to a STD clinic and everyone knows you've got a STD. I think it [income status] does effect and not just herpes, but in syphilis and everything, gonorrhea, HIV. I have ladies that won't go to the AIDS clinic on Broadway because if you do walk in the door everyone will know. I have ladies in the AIDS program tell me "I'm not going there, they will know and people will talk."

Disease Intervention Specialists call Numbers. Their job is to interview patients; record symptoms and contacts; offer HIV testing and provide pretest counseling. They also determine if Stat rapid plasma reagins (RPR's) are needed to screen for syphilis. Following the interview and blood work, patients wait to be seen by a health care provider.

Patients do not know which provider they will see. They are essentially seeing a stranger that they may never see again. Because of the limited options for care, low income women do not have the resources to change providers if they are not satisfied with the delivery of health care services.

Temporal Issues

In this setting, there is little time or opportunity to come to know the person being seen. Time with the health provider is focused on the chief complaint.

Maybe that's a reflection of where I work because we have to stay so focused. You know you don't have the gift of time and you have to make a communication in what you say at the time-make a difference because you are probably not going to have probably an ongoing relationship with this client. It's not going to be an OB/GYN patient that's going to be coming to see you every, you know, every month or two months or something. You may not see them ever again.

The perception of time available to spend with women diagnosed with GHSV impacts the quality of the care received. For example, some HCPs perceive they do not have time to review past sexual histories. One ARNP working at PHU A stated:

I can't ask these women [women with genital herpes] about their sexual histories. It would be like opening Pandora's box and we simply do not have the time to discuss all that. I focus on the complaint of the day. I diagnose and treat what they come in with - that's our job.

Perceived available time is also an issue following the diagnosis of genital herpes. HCPs vary in the amount of time they perceive is necessary to spend with women who have been diagnosed with the virus. One woman described her experience this way:

He [the doctor] said this is herpes and he examined me internally and said "Well they're all over. This is your first outbreak". And I was totally, everything just flashed before me, everything in my life just flashed before me. I didn't move for a short time. I didn't even know where I was and the doctor left me in there and he went out, you know he had other people to see. After a while I just left.

Other providers described "taking the time" they need to spend with women who have been diagnosed with genital herpes. An ARNP in PHU B identified time as an issue in counseling patients.

I think it takes more time to counsel someone especially if they are upset when you tell them, if they get emotional, if they cry, I feel like you need to spend more time with that person and so I think it takes more time for the health care provider with that patient and since you have a schedule and you built in so many people and you try to serve people in a timely manner, but if I need to be with someone, I take the time.

A strategy for "taking the time" is to leave the patient, see other patients and return. Leaving and returning gives the patient time to let the diagnosis sink in and then have increased time with the provider while allowing the provider to stay on schedule.

I take the time and even if I have to leave her [the patient] alone for a few minutes and come back, I would do that and let them have the time they need. I would never send anyone out distraught; I think as a health provider, time is not a problem but an issue because you need time for these people.

Being seen and treated could take all morning, depending on a woman's position in line, her diagnosis, and whether or not she needed lab work or injections. Many people came with coffee and food anticipating a long wait. There were no vending machines or public phones available in the waiting area. Leaving the waiting area meant possibly losing one's place in line. A small television mounted on the wall provided the only diversion.

Staff workers report the average length of time it takes to be seen is 2 hours. However, it can take much longer. One interview was cut short because the participant had been at the clinic 4 ½ hours. She arrived at 7:30am to secure a number and a place in line. At 12:00pm she was ready to leave and agreed to be interviewed even though her toddler was being difficult and her mother was waiting in the car.

I don't mean to rush but I have to take my father to the doctor at 1:00pm. My father just had rotor cuff surgery and my mom's been waiting for me downstairs since 7:30 this morning.

For low income women, the time spent waiting to be seen was a barrier to receiving health care. Those that were employed frequently risked forfeiting wages and/or losing their jobs to take an entire morning off to go the

clinic. Upon request they were given signed forms indicating they had been seen at the health department. The forms included the date of service as well as arrival and check out times.

Clinic hours of operation can also be a barrier. When a low income woman knows something is wrong outside of clinic hours, the emergency room (ER) may be her only available option.

Emergency rooms frequently have a gynecological (GYN) room in the back set up for pelvic exams. There is reluctance on the part of staff to having the "muff room" assigned to them because of the time it takes to work the room.

There is a real almost desire not to have that room [Gyn room] because that whole concept is sort of more work and less pay off. Just the mere invasiveness of having to completely undress and then having them dress plus waiting for their labs. You draw their labs and then they have to hang around and wait. It has been my experience that most nurses don't enjoy having that room. Pelvic exams require the presence of a female in the room. It has become common to assign female nurses to assist with pelvics in the ER where the majority of physicians are male. The room is so disliked that at times room assignment becomes an issue between male and female nursing staff. And it even became an issue with the fact that there were so many male nurses and they weren't given that assignment, so, the female nurses started to really have an attitude about that. It's like, you know, male and female doctors have to do this, why don't male nurses have to do this.

Women presenting at the ER with pelvic or genital pain are generally assigned a non-emergent, low priority status. ER staff frequently sees female problems of this nature as an abusive use of the ER despite high levels of pain. Low income women are discouraged from using the ER for "female problems". One strategy is to tell them that their condition is not an emergency and that they will have to wait a long time to be seen and treated. Non-professional personnel employ this strategy in some ER settings. An ARNP described the practice.

Basically they [non-professional ER staff] told her that they would see her but that she had a really long wait and so she didn't stay because she had a four month old baby with her and no one to help with child care.

In this case, "turking" or sending undesirable patients from one facility to another, continued:

It was on the weekend and they knew the medi-center was open and they just sent her. So she went to the medi-center and the medi-center treated her for a UTI and told her that she should come and see me. I think they were clear that she needed a vaginal exam and they weren't gonna do it. So basically they just turfed her.

Pelvic exams are time consuming and take the emergency physician and a nurse "out of the department" for a period of time leaving them unavailable for real emergencies.

Viewing low income women with genital herpes from this perspective is reflected in the care provided. One participant in the study received her initial diagnosis in the emergency room and described her experience as cold and methodical.

They were very cold and just kind of methodical and kind of did what he [the doctor] had to do and left. Which was fine for me. I just wanted it over with.

An ARNP described the ER diagnostic event this way:

Most of the time if a physician would put someone up and would find herpes it was like they just blew off the rest of the exam, like this is what the problem is - it's self limiting - go home. I have never seen an ER physician treat herpes at all. They are not going to get involved with anything that's not an emergency and herpes is certainly not an emergency.

Travel and Child Care Issues

Child care and transportation were also seen as barriers related to time and location of the STD clinic. In the public health system, women with a suspected STD have to be seen at a STD clinic. General health clinics in the system do not routinely perform pelvic exams or treat STDs. The STD clinics serve large geographic areas, requiring some women to travel significant distances. Low income women frequently do not have adequate transportation or funds to secure transportation. Travel time increases the overall time involved in diagnosis and treatment.

Increasing overall time also increases the burden of childcare. Many of the women attending the STD clinic brought young children with them because they had no available childcare.

Knowing Something Is Wrong

The critical event of being diagnosed with genital herpes begins for the individual with the fear of knowing something is wrong. Women in the study experienced physical symptoms telling them something was terribly wrong and were fearful of what it might be.

Most people come in a little bit scared really scared, and they don't have enough knowledge about herpes when they find out that they have it [genital herpes].

The intensity of the symptoms experienced prior to diagnosis varied. Some of the women in the study described discomfort such as itching or burning in the genital area. Other women described pain that was incapacitating. It was common for women to struggle to find the words to describe their symptoms and their anatomy.

Um A bump came...I don't know how to say, its on the bottom and sides [as she is pointing to genital area] and like it come and stay like for a week and um it was bothering me [painful and itching] so I went to the doctor.

Oh God! Umm oh man, it 's a constant itch to where you know you shouldn't scratch it but you know what I mean, ahh - it's irritated but you have to and then

there is sometimes when it's a shooting pain in the in the area and it burns sometimes. It is the absolute worst. I can't wait until they find a cure.

Um. It was painful to walk. I couldn't walk. Um... I felt like I had blisters down there.

I was in so much pain. I couldn't go to the bathroom. Every time I went to the bathroom I would bite down on a towel and I would like lubricate and go to the bathroom and just it felt like pebbles that are coming out of your butt and it burned I mean sharp pebbles, you know like rocks you can't pass, but pieces of glass.

For two or three weeks I couldn't sleep, I couldn't sit on my rear end. I itched. I cried.

Some of the women interpreted the meaning of the initial symptoms in the context of health problems they had experienced in the past.

Back in 1993, I just had an outbreak one day and I thought it was a yeast infection because it was itching and then I went to the doctor and he told me what it was.

Um. I had kind of an outbreak, I really didn't know what it was, um, I thought it might be a urinary tract infection.

The itching and noticing there was something down there. The burn, there's a tingle, when I went to the bathroom. First I thought it was a urine infection. So I went to get some medicine for a urine infection. Then I realized there was something down there. I examined myself basically and then I asked my mom to take a look and she said you have sores down there.

All of the women participating in the study had symptoms severe enough to seek medical diagnosis and

treatment. Because of the location of the discomfort, "down there", most of the women suspected it was a sexually transmitted disease and sought medical attention in settings known to perform pelvic exams.

I knew it was some kind of sexually transmitted disease right away, because I had never had anything like this before.

Health Care Provider Response to Diagnosis

Health care providers struggle with presenting women with the diagnosis of genital herpes. The incurable nature of the disease coupled with its complex social ramifications set the stage for a difficult conversation with the patient. The diagnosis of genital herpes places HCPs in the uncomfortable position of having to present bad news and telling patients they have little to offer them in the way of treatment or comfort strategies.

I'd far rather tell somebody they've got gonorrhea or chlamdia than HPV or herpes.

I think it's the most difficult sexually transmitted disease to deal with, just because you don't know where you got it and there is no cure for it and the accusations ... people just want concrete answers and unfortunately we usually can't give them any concrete answers.

At the root of this struggle is the uncertainty associated with herpes. Medical knowledge in general is engulfed and infiltrated by uncertainty (Katz, 1984).

Herpes is no exception. Currently there is no cure or vaccine for GHSV. We are not able to say with any certainty how the herpes virus becomes latent, when or if, patients can expect future outbreaks, what the severity of these outbreaks might be, whether or not individuals will have good response with available medications, or how to adequately control the spread of the virus to others.

Uncertainty makes HCPs uncomfortable. Renee Fox (1957) identified three sources of medical uncertainty: incomplete or imperfect mastery of available knowledge; limitations in current medical knowledge; and difficulty in distinguishing between personal ignorance or limitations of present medical knowledge. Medical uncertainty is a source of stress for health care providers.

People come to HCPs for definitive diagnosis and effective treatment. The traditional role of physicians and other health care providers as healers places importance on the values of faith, hope and reassurance (Katz, 1984). In this context, healers are expected to be certain in their knowledge and to be bearers of good news. Acknowledging uncertainty is opposed by tradition. Therefore, great tensions are created by the conflict between the HCPs quest for certainty and the reality of

medical uncertainty (Katz, 1984). A diagnosis of genital herpes is perceived by HCPs as bad news because there is no cure or effective treatment for eliminating outbreaks and disease transmission. Therefore, a diagnosis of genital herpes makes HCPs uncomfortable. One ARNP summed it up by saying:

And you know in a medical culture, we are used to being able to fix a lot of the things that we find and I think that because herpes isn't something easily treated and for sure not cured, and you kind of see that it's self limiting. There is no medicine to give you, you know, to take care if it and get it over with - it's not a comfortable thing for us [HCPs].

One strategy for managing the stress of uncertainty is to brush it aside, to speak with certainty, when moving from theoretical to clinical applications of knowledge and when talking with patients (Katz, 1984). Health care providers are able to gain control over medical uncertainty by acquiring a personal treatment philosophy and exercising clinical judgment or preference without questioning their philosophy (Light, 1979).

HCPs present low income women the medical story of genital herpes. They focus on what is certain, scripting information as medical "facts". In addition, they do not acknowledge personal preferences in treatment philosophy, such as whether to begin suppression therapy with an

initial outbreak or obtain confirmatory cultures. Viewing genital herpes strictly from a medical perspective tends to present a conceptualization of the disease that is separate from the individuals experience of the disease. Therefore, HCPs do not question whether the information provided is meaningful in the lives of low income women. The reality of herpes demands that HCPs acknowledge medical uncertainty. However, avoiding a full discussion of what is not known or what is personal treatment philosophy allows the HCP to give the appearance of certainty. While avoiding uncertainty may increase the comfort level of the HCP, it leaves little opportunity for open discussion of the struggle of living with herpes.

Low Income Women's Response to Diagnosis

Participants in the study varied in their response to being diagnosed with genital herpes. Shock, denial, questioning, and anger were common. The responses did not follow a linear progression. At times participants experienced responses concurrently, such as denial and shock.

Shock

Low income women in the study expected to hear they had an STD, they didn't expect to have genital herpes. The diagnosis of genital herpes came as a shock to many of the participants. A shock is defined as something that jars the mind or emotions as if as if with a violent, unexpected blow or a severe offense to one's sense of propriety or decency, an outrage (Morris, 1981).

I knew it was something, I just didn't know it was herpes. You never think herpes.

Well as far as they, I, the nurse, um just starting I guess, just a new nurse, and um she didn't know what it was so she like left the room and went and got another nurse and than I had people like three or four people in and out of my room the whole time. In the meantime, nobody's telling me anything. Until the lady I just saw just said finally I have herpes. I was in denial (pause) and shock (pause) big time.

Expressing shock upon being diagnosed with genital herpes was associated with the secrecy of the disease. Because herpes is a stigmatized disease, no one talks about it openly. Because it is not talked about, people believe it is not prevalent in the community. This belief supports the inaccurate perception on the part of the women in the study that they are at low risk of being exposed to GHSV.

I mean you don't hear people talking about the herpes. You know it's [herpes] very rare. I see it [herpes medications] advertised on TV but I don't hear people

talking about herpes that much, they are always talking about AIDS. I don't know anyone with it.

Denial

Genital herpes is an incurable, communicable, highly stigmatized sexually transmitted disease. It was common for women in the study to initially refuse to believe or deny that they could have herpes. They didn't want to believe that they could have an incurable STD that would remain contagious throughout the rest of their lives.

And then it didn't go away, it turned into a little sore and I decided to go to the doctor and I was completely blown away on the table - he said 'you have herpes'. And I said 'I can't have herpes, what do you mean?'

I think it can't be. For me herpes is the worst thing, the one worst thing. There is no sickness worse than herpes.

Questioning

Upon hearing the diagnosis of genital herpes, most of the women in the study said they knew very little about GHSV. Unfamiliarity with the disease left the women unable to determine the meaning the disease would have in their lives. Therefore, many of the women in the study had questions. It was interesting to note that several of the women knew some of the medical facts but described themselves as knowing "nothing".

First I don't know what it was. I don't know what is herpes?

I didn't know anything about herpes. Nothing really. Only the fact that I know you can't die from it, that you can, that it is treatable and that you can have outbreaks and when you do have outbreaks you shouldn't have sex. That's about the only thing I really know about it.

Because I didn't know what it really was. I mean, I knew it was a sexually transmitted disease, but, I didn't know if it was going to go away or come back or stay or how it going to effect me and my life and having kids and getting married and will it make a difference to my husband or to my boyfriends.

Um, I didn't know at first. I didn't know much about herpes. I heard about it generally, but I didn't know in depth what it really was about.

The perception on the part of some of the healthcare providers was very different. Several HCPs believed women presenting with herpes knew what they had and that they knew their partners had herpes also.

In my experience, I really believe that most of the time when they come they know that they have herpes. I really don't think that is comes as a big surprise to them. And often times they actually have partners who know that they have herpes and have encouraged them to actually come in.

HCPs make a distinction between knowledge of herpes and knowing you have herpes.

I think a lot of them do know they have herpes but they don't know what herpes is.

They are not knowledgeable. They come in here and they say 'Well you know somebody said that they think

they [partner] have herpes and I [participant] may have gotten it'. But they want medication for it without understanding that the medication can help the lesions heal, but it doesn't cure the disease. And I think that's the biggest piece of the lack of understanding.

Oh yeah, some of them I've had ask well can't you give me a shot or some pills. It's, like, well no I can't. It doesn't work that way, you know. But they hear out in the community that you come in and you get your shots or your pills or whatever and it's done and it's all taken care of. And I certainly wish it were that way. It would certainly make things a lot easier.

Anger

Anger was one of the most common responses to the diagnosis of genital herpes. Anger included expressed indignation, displeasure, blame and/or betrayal associated with having GHSV. The anger expressed by the majority of the participants had little to do with the specific diagnosis of herpes itself. In the majority of interviews, the women directed anger at themselves and/or at their partners. They were angry with themselves for trusting their partners and for not insisting their partners use condoms. They were angry because they knew better.

I can't believe I was so stupid. I know better. I know to use condoms. I'm just so mad--We used condoms the first time--I'm just so angry at myself for being so stupid and now this is forever.

When I first noticed the sores I was enraged! I made my mother look because I never had anything like this!

I'm very angry. And the fact that I trusted someone that I loved for so long to transmit this to me.

Anger directed at the partner frequently took the form of blaming. The women made clear distinctions between partners that knew they had herpes (or should have known) and partners who didn't know. If the partner knew, participants expressed a sense of betrayal.

I had always been with one person I had trusted and he had unprotected sex and it's like my trust of men has hit rock bottom now. Basically they all can not be trusted now.

Whether he knew it or not, you know, he should have used a condom and not only that, after only being separated a few months and knowing that he had sex with somebody else makes me very angry.

A couple of years ago I just thought he was an idiot. Today, I think he knew and, you know, I think he knew. With me being as young as I was that he should have let me know. Let me deal with it.

I was home being faithful and he was out there running around and I just thought it was unfair and I didn't deserve it.

Summary

For low income women, the critical event of being diagnosed with genital herpes begins with the fear of knowing something is terribly wrong and ends with knowing that the disease you have is incurable. It ends with

knowing you may be facing a lifetime of unpredictable, painful outbreaks and that you can give the disease to lovers and pass it on to your unborn children.

The socio-political context of being diagnosed with an incurable, communicable, sexually transmitted disease influences how low income women respond to the diagnosis and the value woman place on the disease. In addition, educational, diagnostic, stigma and time issues associated with the diagnosis of GHSV directly affect the women.

In this study exploring living with genital herpes, fear emerged as the basic social psychological problem low income women with genital herpes face. The critical event of being diagnosed with genital herpes begins a trajectory of fear that low income woman must struggle to manage in their daily lives.

CHAPTER 5
FEAR: THE BASIC SOCIAL PSYCHOLOGICAL PROBLEM

Introduction

Grounded theorists seek to explain how individuals define reality and how they respond in relation to that reality (Chenitz & Swanson, 1986). The basic social psychological problem represents the major problem faced by participants who experience a particular illness or event. In this study that explored the experience of low income women living with genital herpes, the major problem identified in the lives of the participants was fear. Participants described living with fear as an ever present aspect of their lives following the critical event of being diagnosed with genital herpes. This chapter will define fear, describe types of fear experienced by low income women in the study, and discuss the path or course of fear known as the fear trajectory.

Fear

The term fear denotes an emotion excited by threatening evil or danger with a desire to avoid or escape it (Fernald, 1947). Prior to the diagnosis of genital herpes, low income women experienced the fear of knowing something was wrong. Once the chronic, incurable, transmissible, unpredictable, stigmatized nature of the virus became known, additional fears emerged and living with fear became a permanent part of their everyday life. Fear caused total upheaval in the lives of the women in the study. Participants overwhelmed with fear felt out of control of their lives.

I feel I was in control of my life before. I just don't feel like my body is mine, my life is not mine. I feel like it's been taken over. Because I'm not in control of it, I just can't control it, it's just something that's going to happen and just because it's not happening now or I'm not having an outbreak doesn't mean that it's not there. You know, so my life is not mine. That's the biggest fear I have. I'll never be in control of that [genital herpes] unless they find a cure.

No matter what I do this is not going to go away. I never thought something like this could happen to me. The bottom line is I can't change it [having herpes]. I can't control it. I'm afraid it controls me.

Uncertainty played a role in the degree of fearfulness experienced by women in the study. Mischel (1988) defined uncertainty as the inability to determine the meaning of

illness-related events and occurs in situations where the decision maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking. Grounded in the social values of rationality, prediction and control, uncertainty itself becomes a source of fear and has the potential to disrupt the person's sense of control and direction in life (Mischel, 1990). Uncertainty impedes the formulation of a plan of action, limiting an individual's ability to adequately appraise a situation (Mischel, 1988).

Following the critical event of being diagnosed with genital herpes, low income women in the study faced a lifetime of uncertainty. In this study, the more uncertain participants perceived their situation to be, the more fearful they were. Fear associated with genital herpes permanently altered the physical, social, and sexual lives of the participants.

Types of Fear

Low income women in the study described fear as a constant, pervasive aspect of their lives after being diagnosed with genital herpes. Although fear was described in a variety of different ways, three main types of fears emerged from the data. Women in the study were fearful of

suffering physical pain, disclosing their diagnosis to others and passing the virus on to others.

Fear of Pain

Primary and recurrent GHSV infections tend to be more severe in women than in men (Tyring & Sadovsky, 1996). One explanation for this is that virus infections spread easily over moist surfaces (Habif, 1995). Large areas of the female genitals may be covered with painful erosions. During primary infections, inflammation, edema, and pain may be so severe that urinary retention occurs necessitating catheterization, bed rest and/or hospitalization for intravenous anti-viral intervention (Habif, 1995). In this study, the severity of pain experienced with the primary infection influenced the degree of fearfulness participants expressed. The greater the pain experienced with the primary infection, the greater the degree of persistent fearfulness.

While recurrences tend to be less severe than primary or initial outbreaks, pain experience is unpredictable. Some recurrent outbreaks are more painful than others. Nearly 90% of patients with symptomatic GHSV have a median of four (4) recurrences per year (Tyring & Sadovsky, 1996). The women in this study reported ranging from two (2) to

thirty-six (36) recurrences per year. The median was five (5) recurrences per year and the mode was six (6) recurrences per year. Low income women in the study could not predict the timing or severity of their outbreaks with any certainty. Most of the women described early warning signs that a herpes outbreak was eminent before visible signs of the virus were seen. Early warning signs or "prodrome" included itching, burning, tingling and/or pain at the site of previous herpetic lesions.

I feel that tingle there [genital area] and I think Oh my God here it [herpes] comes again. I get really scared because the pain can be so bad. I never know how bad it's going to be.

The prodrome involves irritation along the nerves affected by HSV. Because nerve pathways are involved, nerve irritation can lead to pain in non lesion sites such as the buttocks and legs. The pain associated with the prodrome and fear of what might follow caused one woman to take to her bed.

I feel victimized by this. It's like Why me? Why this? I would just cry and, you know, take to my bed, not only for the ache in my leg as much or more for the fear of the pain, the not really knowing how much it was going to hurt this time. It is so devastating to think 'Oh, I've got to do this [herpes outbreak] again'. Even if I do this for three or four days, I'm not going to get any relief until maybe the fourth or fifth day. It just impedes my life so much.

The uncertainty of not knowing how painful an outbreak will be left the women anticipating the worst. Women spoke of worrying and waiting everyday for the pain of herpes lesions to return.

I always feel uncomfortable, I feel like it comes back any time. I worry, I wait.

It's irritated and there are times you have this shooting pain in the area and it burns sometimes. I'm always on the edge basically to make sure I don't have another outbreak. It's basically way beyond my control. I'm just a little bit more cautious. Umm, a lot more cautious everyday.

Recurrent symptoms ranged from subtle to incapacitating. Over time, a few women in the study described a lessening in the fear associated with recurrences as the number and severity of their outbreaks decreased. Recurrences were described by this group as uncomfortable but not painful.

It's really painful when you first get 'em, your first outbreak. I mean I couldn't even walk. That's how bad it was. I can walk now. There is really no pain. It just itches really bad like you got an infection down there or something. I can live with that.

These women were hopeful the worst was behind them, that future outbreaks would be controlled by their immune system or through anti-viral medications. However, they remembered the pain of previous outbreaks. Remembering

caused them to worry every time the familiar itching, tingling or burning of the prodome sounded the alarm that an outbreak was on the way.

I use to have a lot of pain. That was the worst. Now I feel it coming, you know, itching and burning and think 'I hope the medication will stop it in it's tracks or that it won't be any worse that the last time. It's not all that bad now'

Decreasing frequency and severity over time could not be predicted or counted on by everyone. One woman described her pain as increasing over time.

I just recently got over an outbreak maybe three weeks ago. That was totally the worst I've ever had and I don't know why. Maybe I was worrying too much or something but it was the absolute worst. It was terrible. I can't wait until they find a cure. It's hard to live not knowing when you're going to be in total pain.

Fear of Disclosure

The women in this study clearly articulated fears about disclosing GHSV to others. Fear of disclosure was caused by the stigma associated with having an incurable sexually transmitted disease. Sontag (1978) noted that some diseases carry such a stigma that any discussion of the illness and their consequence is forbidden. In his classic work on stigma, Goffman (1963) described the stigmatized as being socially discredited on the basis of an undesirable attribute that sets them apart from normal

society. Persons who are stigmatized are not accepted by "normal people" (Goffman, 1963).

My biggest fear is people finding out. The obvious people, my family, closest friends. That's my biggest fear. Because I want to run away and hide. I felt weird and odd. Will people look at me and say and know? I just felt like everyone knew. I was just scared, real scared.

Stigma complicates disclosure and contributes to the fear of living with the disease. Women in the study were fearful of disclosing they had genital herpes to family and close friends.

My friends don't know. My mother knows and my aunt knows but my mother is like, she refuses to talk about it. When I told her she said 'I told you so' and she really wasn't supportive and said forget it and I act like - I don't talk to her about it. I can tell she looks at me differently and the way she talks to me and the way she acts towards me, it's different but I ignore it and I just try to avoid it [discussing herpes].

The stigmatized are often considered not quite human, inferior and dangerous Goffman, (1963). Women in the study expressed fears that people would look at them differently if their diagnosis was known and that their friends and family would be afraid of catching the virus from them through causal contact. Women described being fearful others would find them dangerous.

I think it's people will look at me differently. Most people wouldn't want you to use their bathrooms if

they knew. Most people have a big fear of it. You know, if I go to my girlfriend's house and she knows and I use the bathroom, maybe it's just me, but I just feel like, you know, what is she thinking? Is she gonna be going behind me cleaning her bathroom after I leave and all that. Maybe that's what I would do. Herpes changes things.

The women spoke of being unsure of how their disclosure would be received. Barker (1948) [see Goffman p.13] suggested disclosing a stigmatizing condition involves "living on a social-psychological frontier". Each disclosure of GHSV is akin to facing a new situation with uncertain outcomes. Because responses to disclosure are uncertain, questions of who, when, where, and how to tell others arise (Goffman, 1963). According to Goffman (1963) we tend to impute a wide range of imperfections on the basis of the original one (p.5). Because GHSV is transmitted through sexual contact, women were fearful of being labeled as bad girls.

I would never tell them (family). It's not something I would ever say to them. I would tell my family I have HIV first. Even though you get it the same way, sexually, but I guess because AIDS effects the whole body and herpes is just there. To me it's just a stigma attached to your private parts, the most private part of you. That's why.

No one in my family knows. I guess I'm embarrassed. I've always been very private, if it's something very personal like, you know. They don't know any thing about my sex life, you know, I just don't broadcast it.

Women were fearful of being labeled promiscuous sluts.

Deciding to tell them would be like Oh my God they think I'm a slut and I'm not. I'm not a slut and I'm not from the streets but they would think so.

Women were fearful of being labeled unfaithful.

I told him 'I have herpes' and he didn't look stunned, he just said 'you do?'. I said 'yes' and he said 'who have you been with?' and I said 'who have you been with?' You know, the usual back and forth defense thing. We blew up and he denied. To this day he denies he has it.

Keeping secrets. Family and close friends are normally the first people we tell our troubles to. Because of the stigma placed on genital herpes, women in the study were fearful loved ones would no longer accept them if they knew their diagnosis. Keeping secrets from family and close friends placed a heavy burden on the women that chose not to tell.

My family doesn't know. So I always feel like I'm living this big secret. I'm living with this big secret because there is no way I would tell anybody. There is no way.

Sometimes I want to talk about it with a friend or my mom and then I think no. I would rather suffer this alone than risk them finding out.

Living with the secret of genital herpes caused some of the women to actively anticipate and worry about how they would be able to keep the diagnosis hidden over time.

For example one woman worried about her mother finding out if she had to have a C-section when she delivered her baby.

I'm pregnant. Nobody knows I have this [genital herpes]. If I end up with a C-section what am I going to tell my family? My mother will want to know why I had to have a C-section. What if the doctor or nurses say anything? People know why you're getting a C-section.

The secret of genital herpes is sometimes kept from HCPs too. Low income women frequently do not have a choice in who their provider will be. Women coming to a public health unit for treatment often see whoever is available at the moment. In this context, trusting relationships are difficult to develop. Women in the study feared they would be treated differently if the HCP knew they had herpes. They told providers on a need to know basis only. For one woman, the risk of disclosure was greater than the risk of keeping the secret.

When they [HCPs] ask me if I have anything I just said 'no'. Then I wonder if that's going to, you know, interfere with medications or whatever but I do fine and I say no because I'm too embarrassed of what they will think of me.

Another women came to the STD clinic at the public health unit because she suspected she had herpes. She didn't want her regular Medicaid provider to know:

I had to come here because I knew I would be seen today. I thought it might be herpes - it's so ugly.

I couldn't see my gynecologist. He delivered my two girls. I've never had anything like this. I could never look him in the eye again.

Once the secret of genital herpes is disclosed to a HCP, women were reluctant to change providers. Changing providers might necessitate another disclosure. One woman described not wanting to change HCPs because the current provider knew she had herpes and was supportive. She felt she was lucky to find someone understanding and did not want to risk changing providers and being forced to disclose again.

I had to have her [HCP]. I didn't have a choice. I was afraid of how they were going to look at me or how they were going to judge me but I told her and she was real supportive. She helped me and she gave me a lot of information. A lot of pamphlets and stuff and she still talks to me. She's more like a friend. I think I'll never change because of that.

Disclosing recurrences. Most of what has been written about disclosing genital herpes focuses solely on telling someone who doesn't know, a new partner, a close friend or family member, etc. Women in the study were also fearful of telling their partners they were having a recurrence. Recurrences interfered with sexual activity. Telling the partner they had a recurrence was seen by some of the women as a regular reminder they were not normal - that they had a sexually transmitted, incurable disease.

With my husband I never said anything [about recurrences]. I just stopped being with him. I just completely pulled away. With my next partner, he had it too so I never said anything about an outbreak because I didn't think it really mattered. It was too painful for me to bring it up. A regular reminder that our lives were ruined.

I don't say anything. He just knows. If I'm lying in bed in the middle of the day he knows something is wrong, that I'm in pain. I don't say the word herpes. It makes me so mad. It stresses me out.

Disclosing recurrences was especially difficult if the women believed their partner did not have the virus.

I always worry what he might be thinking when I tell him I can't have sex. Does he wonder where I got it [herpes]? Does he worry if he is going to get it?

Women who were in a relationship with the person they believed was the source of their infection worried less about disclosing their recurrences. They were not fearful of what their partners might be thinking.

I just tell him I got another outbreak and he usually says did you take a pill or what are you being stressed out about or something. He's the one that gave it to me actually. I've only been married two years in January. At first I was mad at him, but then we talked. He didn't know he had herpes. I made him go to the doctor to tell me if he had it for sure or not. He did.

I would just come out and tell him I'm having an outbreak, and I would go to the doctor just to confirm that.

Fear Of Passing It On

The importance of preventing the transmission of the virus to others is stressed in the medical story told by health care providers. All of the participants in the study were aware that genital herpes was incurable which meant they would always have it. They knew herpes was contagious and were fearful that they might transmit the virus to someone else. Participants referred to transmission of the virus as "passing it on".

I mean I have the virus already, I will always have the virus, I could never have an outbreak again, but I still will always have it. I guess you could say the main concern would be not to pass it on, you know.

I never want to pass this [herpes] on to anyone else. I wouldn't wish this on my worst enemy. I really wouldn't.

HSV-2 usually resides in an inactive, state in a nerve bundle at the base of the spine (Preventing Transmission, 1997). Once activated, the virus travels along nerve pathways to the surface of the skin where it may or may not cause symptoms (Preventing Transmission, 1997). It is during this active phase that herpes may be passed through skin to skin contact.

For the women in this study, the fear of passing it on was based on concern for others, the absence of tools or

prevention strategies that guarantee they won't pass it on, and knowing from their own experience how someone would feel if he or she got herpes from them. The women were fearful of transmitting the virus to sexual partners, their unborn children, and of re-infecting themselves.

Passing to sexual partners. Herpes is most easily spread during sexual intercourse when lesions or other symptoms are present. Recent studies show that it is also possible to pass the virus through viral shedding when an individual is asymptomatic (Mertz, Jones, & Mills, 1988; Wald, Zeh, Davis & Corey, 1996). During viral shedding, viral particles come to the surface of the skin without causing noticeable symptoms. Shedding patterns vary widely among individuals making it difficult for persons to know when they are contagious (Preventing Transmission, 1997). Therefore, asymptomatic shedding heightens the fear of passing it on to partners. Even condoms do not provide complete protection. Herpes lesions and shedding sites can occur in areas that are not covered by conventional condoms.

Herpes can also be passed during oral sex. Persons engaged in oral sex with an active oral lesion could pass the virus to the genitals of their partner. The virus can

also be passed from the genitals of one partner to the mouth of another partner, although this is rare (Preventing Transmission, 1997). Therefore the act of having sex, even protected sex, always poses the threat of passing the virus.

In contrast to being fearful of passing the virus to others, one of the women in the study wanted to make sure the lover she thought gave her herpes did in fact have the disease. She was angry with him because he had forced her to have anal intercourse. Following anal intercourse, she experienced herpetic lesions in her perianal area. She had been told by her HCP that it was not possible to be certain of when she had been exposed to the virus or who had passed the virus to her. However, she felt certain her lover had given the virus to her and deliberately had unprotected sex with him to "make sure" he had it. She reasoned that because he had the virus, unprotected sex did not place him at risk.

Passing to unborn children. For the women in this study nothing was as devastating as the thought of passing the virus to their unborn child. Neonatal infection is serious but relatively rare. Infants of mothers who develop a primary infection during pregnancy are at greater

risk for morbidity and death than the infants of women who experience a recurrent infection during pregnancy (Porber, Corey & Brown, 1992). The timing and type of GHSV infection experienced during pregnancy influence morbidity and fetal death rates.

Increased frequency of spontaneous abortion, still birth and congenital malformations are associated with primary infections occurring during the first 20 weeks of gestation (Kulhanjian, Sorovsn & Au, 1992). The rate of fetal complication is greater than 40% when GHSV infection occurs during the third trimester (Brown, et al., 1987). Complications include aborted pregnancy, premature labor, in utero transmission and transmission at the time of delivery. Primary infections occurring at the time of delivery place the infant at high risk of acquiring the virus (Habif, 1995). The mortality rate for infants born to women experiencing active primary infections is about 50% in the absence of anti-viral therapy (Habif, 1995). Neonates are usually exposed to the virus during delivery, but in utero transmission also occurs. Survivors commonly have ocular and neurologic complications (Habif, 1995).

For women with a history of genital herpes who have no symptoms at the time of delivery the transmission risk is low. If inadvertent exposure occurs, the risk that the neonate will acquire the virus is still less than 8% (Toltis, 1991). However, the risk is high enough for the American College of Obstetricians and Gynecologists (Guidelines for Women's Health, 1996) to recommend cesarean delivery for all women who have active lesions at the time of delivery.

Clinical signs and symptoms of neonatal infection present between the first and seventh day of life (Habif, 1995). "Infection can be limited to the skin, eyes, or mouth, or can effect the central nervous system (CNS) or visceral organs, causing hepatitis, pneumonities, intravascular coagulopathy, or encephalitis" (Habif, 1995, p.35). Neonatal death is unusual in cases limited to the skin but occurs in 15%--50% of the cases involving the brain or disseminated disease (Whitley, Arvin, & Prober, 1991).

Not surprisingly, women who were pregnant at the time of the study interview most acutely felt the fear of passing the virus on to their baby. Several of the women in the study were diagnosed with herpes during their

pregnancy. This heightened their fear of passing the virus to their baby.

My main problem is making sure that my baby doesn't catch it. Well my baby can definitely catch the virus which doesn't make me too happy. I had meetings with the doctors and researched on it, you know, for the baby not to catch the virus and that mainly has been my main concern lately.

I'm really worried now about the baby. I hear that once the water's still intact, there is not a chance of the baby getting herpes, but I don't know, I'm still worried.

I'm afraid of my baby getting herpes. Because, if it's so hard on me, what's it like for a newborn? There's just no way I want that to happen.

Fear of passing the virus to their baby was combined with a sense of guilt.

Um, it's like if anything happens to my baby or what not, it would kind of be my fault. You know, kinda like putting the blame on yourself, I guess. Just being stressed out about what's going to happen and, oh gosh, if anything does happen, it's gonna be my fault.

All of the women in the study were of childbearing age.

Fear of transmitting the virus to unborn children was not limited to pregnant women. Women in the study who were not pregnant were also actively fearful of passing the virus.

It doesn't seem fair. I mean I'm not pregnant now, but I would like to have kids in the future if I find the right guy. I could give herpes to my baby. I'm really worried about that.

The fear of potential transmission to unborn children was so terrifying it impacted their thinking about the possibility of future children. Despite the risk of passing the virus on during pregnancy being relatively low for women not experiencing a primary infection, women saw genital herpes as barrier to the joy of having children.

The worst thing about this [herpes] is knowing what you could do to your children. Why should they have to suffer because I was stupid?

I always thought I would have another child. Now I don't. The thought of passing this [herpes] to a baby ends all that.

If I got pregnant she [HCP] told me that it won't hurt the baby as long as I got regular checkups and kept up with whatever, but I still worry. If I'm going to risk the baby getting sick, I wouldn't get pregnant and I feel like I don't have that choice anymore, you know, it's just point blank no. I just feel like I've been cheated out of a lot of good life and I can't do the things that I want to do now.

The experience of having a baby without passing the virus on did not alleviate the fear. Women in the study were still fearful of passing the virus in pregnancies.

I was lucky with my first one. I don't know if I would risk it again. But I would like to have at least one more [baby].

If I have another baby I won't be able to have it vaginally. I'm petrified of that, I don't know, I have one child now, I don't know if I will have anymore.

Some of the women carried the anguish of what might have happened long after their baby was born healthy, without the virus.

Whenever I have an outbreak I really get sad. I cry. I think about my little boy that could of died or been born blinded. I try not to think about it but it's always there.

Women also feared passing herpes on after the baby is born without exposure to the virus. One woman described making plans to be extra sure she didn't pass it on to her newborn.

I know that I am going to be extremely careful as the baby comes with as far as hygiene is concerned, but my biggest concern is after the birth and herpes. I know that it's so easy to transmit it I'm going to wash my hands and make extra sure when I have an outbreak to be careful with the baby.

Passing to self. Herpes is set apart from other chronic illnesses because of the possibility of spreading the disease through autoinoculation. Autoinoculation refers to the spread of HSV from one part of the body to another (Ebel, 1998). Having herpes in one area does not protect you from getting herpes in another area. HSV may appear on any skin surface but seems to prefer mucous membranes (Habif, 1995). Autoinoculation can result when a woman touches an active lesion and then touches another vulnerable place on her body. It occurs almost exclusively

during true primary infections when there are many lesions and high doses of virus present on the skin. For otherwise healthy adults, it is estimated that autoinoculation occurs in 10% of primary infections (Ebel, 1998). Over time the body is able to develop a strong immune response to the virus, making autoinoculation uncommon during recurrences (Ebel). When autoinoculation does occur, HSV most commonly moves from the genitals to a finger or on to the mouth (Ebel). For example, the condition known as herpetic whitlow (herpes simplex of the finger) is most often seen in children with gingivostomatitis and in women with genital herpes (Habif, 1995). Despite research evidence to suggest autoinoculation during recurrent episodes of GHSV is uncommon, women in the study were fearful they were at great risk of spreading the virus to other areas of their body.

I'm afraid of spreading it somewhere else, I mean it is not near my vagina even though the doctor said it could spread there.

They told me you can get this stuff anywhere. What if I get it on my hands or in my eyes? Herpes is horrible. It's so ugly.

If you don't know the signs you wouldn't know what to think. You would scratch and you would bust open that sore and then you're going to get it all over.

Two women in the study had experienced what they described as autoinoculation. In one situation the primary infection was limited to the woman's peri-anal region. Herpetic lesions later appeared in her vaginal area in subsequent recurrences.

I've got this new lesion, it moved to my private parts, the vaginal area. It's only one, but it moved and I didn't expect it to move. I must have touched myself or something. This stuff [herpes] is so scary.

Genital herpes is a term used to denote all HSV infection that is latent in the sacral ganglion at the base of the spine (Ebel, 1998). The virus is limited by the nerve pathways connected to the sacral ganglion but does not always show up in the same place (Ebel). The situation described above is probably not an example of autoinoculation because the lesion remained in the same general area below the waist. For this participant, the event of having a "new lesion" reinforced her fear of passing it to self. She came to see her body as a dangerous other. She was afraid to touch herself in her genital area for fear of re-infecting herself.

I masturbate to help me go to sleep at night, but even that causes paranoia. I use to fall asleep afterward, now I go and wash my hands right after it. I'm afraid so I don't do it [masturbate] as much anymore. I'm afraid to touch myself there.

The other woman who experienced autoinoculation was also the only known HIV positive participant in the study. In immuno-compromised persons, cutaneous or mucosal HSV infection is generally more severe and involves more tissue destruction (Habif, 1995). Under conditions of immunosuppression, lesions take longer to heal and residual scarring is more common (Habif). One recurrence may not heal completely before the next one erupts (Tyring & Sadovsky, 1996). Autoinoculation and systemic spread are more likely in persons who suffer from compromised immune systems. For her, autoinoculation was a very real and frightening concern.

You worry about how this thing is going to spread. Is it going to stay right here [vaginal area]? Is it going to spread to my rectum? Is it going to come up on my back again? I even found a bump on the left rear of my butt back by the rectum, now I'm going 'Oh God, don't let this happen!'. I have to be careful because you can contract herpes in the anus you know, so it's just something I have to be careful with as you would the HIV in general, probably more so. I usually break out by the upper lips of the vagina right about where your pubic hair grows. They'll break out there and sometimes they'll break out on my legs. My arms start itching, you know, that's when you know you're broken out.

The Fear Trajectory of Genital Herpes

The women in the study experienced fear as having a trajectory or path that was influenced by a number of variables. While always present, fear waxed and waned depending upon various physical, social and psychological events in their lives. The work of living with genital herpes involved learning to manage or shape the course of fear.

The concept of trajectory is derived from the work of Corbin and Strauss (1988). In their work, trajectory implies a multi-dimensional course or unfolding of a chronic illness effecting the individual and those around him or her in all aspects of life (Robinson, et al, 1993). A major premise of the Corbin and Strauss Trajectory Model is that a chronic illness course can be shaped or managed over time even if the course of the disease cannot be altered (Smelzter, 1991). Corbin and Strauss believe that the majority of the ongoing work of managing chronic illness goes on at home and rests upon the shoulders of afflicted individuals and their families (Corbin, 1993). While Corbin and Strauss use the term trajectory to refer to the illness course, the term has also been used to

describe the unfolding of stigma in individuals who are HIV positive (Alonzo & Reynolds, 1995).

Genital herpes differs from many other chronic illnesses in the sense that while herpes is incurable; it is not progressive in otherwise healthy adults. In fact, there is some evidence to suggest that the physical symptoms of genital herpes may improve over time (As We Age, 1997). The illness course of herpes is relatively stable, although there is considerable variation in the number and severity of outbreaks experienced by individuals. Uncertain trajectories maximize personal and familial hardships (Corbin & Strauss, 1988). Low income women in this study described fear as being more debilitating than the physical consequences of the illness course of GHSV. This study extends the use of the concept of trajectory to describe the unfolding and management of fear following the critical event of being diagnosed with genital herpes.

Fear, like the virus itself, was persistent in the lives of the low income women in this study. To persist is to continue in or adhere firmly or obstinately to a course (Fernald, 1947). Women in the study described themselves

as never being completely free of fear following the diagnosis of genital herpes.

You carry this [fear] with you always. You can try not to think about it but it's always there. It will always be there.

Factors mediating the Fear Trajectory

Illness trajectory shapes, according to Corbin and Stauss (1988), have two important properties: variability and phasing. Trajectories vary in terms of form, duration and in the amount of work to be done (Corbin & Stauss, 1988). Variability is determined by (1) the nature of the illness and the person's physiological and emotional response to it and (2) management plans developed and initiated by the ill person and health care providers (Corbin & Stauss, 1988). Phasing gives the trajectory its shape and denotes the type of management work to be done.

The fear trajectory of the women in the study fluctuated depending on a number of factors. Mediating factors that emerged from the data included: illness severity, pregnancy, relationship stability, and remembering herpes. Over time, low income women diagnosed with genital herpes learned what factors influenced their fear trajectory and struggled to develop effective

management strategies. (Managing the fear trajectory will be discussed in Chapter Six.) Combined, these factors created the dynamics that affected fear management and the quality of life for low income women with genital herpes.

Illness severity. Illness severity directly influenced the fear trajectory of individual women. The severity of genital herpes was described by the women in this study in terms of how often outbreaks occurred (frequency), how much they hurt (degree of pain), how many lesions were involved (scope of infection), where the lesions were (location), how long they lasted (duration) and how predictable they were (predictability). These factors greatly influenced the unfolding course of their fear trajectory. A trajectory with dips indicating reactivation of the virus, shaped by the severity of the recurrences, reflects the work involved in managing the fear trajectory. For example, women experiencing few, relatively painless recurrences experienced less fear of pain than a woman who experienced frequent, painful recurrences. The lower the perceived severity of the illness, the less fear management work was required.

Pregnancy. The physiological event of pregnancy greatly influenced all types of fear. As described earlier, one of the most horrifying realizations for women is the possibility of passing the virus on to their children during pregnancy or delivery. Women felt "forced" to disclose genital herpes to their HCP during pregnancy in order to adequately protect the baby.

I wouldn't even tell my gynecologist if I didn't have to, but I know I have to so I did. Once you tell somebody, anybody, it can get out, you know?

Because the physical stress of pregnancy impacts the immune system, several women in the study described being fearful of having to suffer through an increased number of recurrences. Because the anti-viral medications have not been approved by the FDA for use during pregnancy, the women also felt an increased sense of loss of control of the severity of their outbreaks throughout the pregnancy. Being unable to adequately control outbreaks might also mean they would have an increased number of recurrences to disclose.

They told me when you're pregnant your immune system is down so that can lead to getting a cold a lot easier or the flu. If you have the herpes virus your immune system being down can bring it [herpes] out too. That means I can expect more outbreaks. Outbreaks that are worse than usual because they say I

can't take the pills [anti viral medication] because they might hurt the baby. I can't even use the cream!

Relationship stability. For the women in the study, changing sexual partners increased the number of times they had to consider whether or not to disclose they had genital herpes and placed them at risk of acquiring additional STD's. Women in the study reported a range of zero (0) to two (2) sexual partners in the past year. With each new relationship, the decision to tell or not tell came up and the fear of disclosure was acutely felt. The women had to weigh the risks and benefits of disclosing or not disclosing they had genital herpes.

Having genital herpes impacted the decision to leave or stay with their current partner. Some women left the partner they believed was responsible for giving them the virus. They expressed a feeling of betrayal and a belief that their partners had been unfaithful. For example, in response to whether or not herpes was a factor in staying with her husband, one woman responded:

I left him. You know, because I felt I was home you know, why did he have to bring it home to me. I was home being faithful and he was out there running around and I just thought it was unfair and I didn't deserve it.

She later expressed fear that having herpes would mean she would not be viewed as desirable partner to someone else and returned to her husband. When asked if herpes played a role in her decision to return to her husband she replied:

I wish you hadn't asked me that. What else was I to do? Where else was I to go? I don't know, he said he didn't have it [herpes]. At least he was willing to stay with me knowing I had it.

Other women stayed in relationships partly because of having the virus.

At first I was angry about it [getting herpes]. But then we talked. He didn't know he had it. It's not like he was unfaithful or anything. They told me you can have it for a long time and not even know it. Anyway, I've got it now. Leaving him wouldn't change any of that.

Remembering Herpes. Several women in the study talked about fear associated with remembering herpes. For these women, just thinking about herpes made them fearful. Thinking about genital herpes served as a reminder that they were no longer able to live a normal life.

I just try not to think about it. Thinking about it makes me scared. There is nothing I can do about it so I just try to keep it out of my mind.

I'm a worrier. I kind of tend to worry about something over and over and over again. When I think about herpes, I start to worry about it over and over and over then I'll find myself maybe a few days later with an outbreak. So I try not to think about it. I tell myself just stop.

Some women described being able to "think" themselves into a recurrence.

I was at a point one time where I was so afraid of having an outbreak I wouldn't even say the word herpes. I was afraid I was going to jinx myself. I was like if I say I have herpes, I'll get herpes and it really almost worked that way. I could psych myself into it [outbreak]. I don't mean like it was voodoo or something I just mean thinking and worrying about it made me upset and I guess the stress would bring it on.

Summary

The basic social psychological problem identified for low income women diagnosed with genital herpes was living with persistent fear that affected every aspect of their daily lives. Pervasive fear made the participants feel out of control of their daily lives. Types of fear included: fear of pain, fear of disclosure, and fear of passing it on. Stigma associated with the virus set the stage for fear surrounding disclosure. Fear was experienced by women in the study as having a trajectory that was mediated by physical, social and psychological events in the woman's lives. Women in the study addressed their fear by learning, over time, to manage or shape their fear trajectory.

CHAPTER 6
MANAGING FEAR: THE BASIC SOCIAL PSYCHOLOGICAL PROCESS

Introduction

Grounded theory seeks to discover a core category which identifies and explains a pattern of behavior considered relevant and problematic for study participants (Glaser, 1978). It reflects the main concern or problem from the perspective of the individuals participating in the study. The researcher consciously looks for a core category when constantly comparing incidents and concepts from the data (Glaser). The core category integrates the evolving theory that enables the researcher to account for a wide variation in behavior. Theoretical properties of the category are identified as the researcher continues to compare incidents and concepts in the data.

A basic social psychological process, or BSP, is a type of core category. It is defined by Glaser as a pervasive, fundamental patterned process in the organization of social behaviors which occurs over time and

goes on irrespective of the conditional variation of place (Glaser, 1978, p.100). As a core category, BSPs must be central to the data, recur frequently throughout the data, connect easily with other concepts, explain as much variation in the data as possible, have clear and grabbing implication for formal theory, and move the theory forward (Glaser 1978).

BSP accounts of the world contribute substantial insight into the practical realities of the day-to-day world by explaining its variation (Glaser, 1978, p.114). BSPs seek theoretical coverage and do not claim descriptive completeness. The only claim advanced is that the BSP explains much of the variation to be found in the actions, interactions, and perceptions found in the collected data from a research site (Glaser, 1978). In this study, exploring the process of living with genital herpes, the basic social psychological process identified in the lives of the participants was managing fear. Managing fear is explained through the delineation of its phases: controlling information, controlling herpes, and moving on.

Managing Fear

According to the American Heritage Dictionary (Morris, 1981), to manage is to exert control over, to make submissive to one's authority, discipline or persuasion (p.792). The verb managing denotes deliberate action taken on the part of an individual to achieve an outcome considered desirable by the individual. The process of managing fear focuses on the deliberate actions undertaken by low income women with genital herpes to regain some control of their lives by shaping the fear trajectory. Through managing fear, the women seek to handle the uncertain events of genital herpes as best they can.

The women in this study felt victimized by the circumstance of having genital herpes. They felt harmed and made to suffer from the condition of genital herpes. Their lives were no longer their own to live as they wanted to; herpes virus had taken over. Pervasive fear made them feel out of control of their daily lives as they tried to work and engage in typical social interactions. Recognition that the course of fear was alterable, even through the chronic nature of genital herpes was not, allowed the women to regain control of their lives and move out of the role of victim.

Women in the study learned to manage fear over time as they lived day-to day with genital herpes. Unlike other chronic illnesses where management work is often divided among the individual, the spouse, other family members, and HCPs (Corbin & Strauss, 1988), the work of managing fear in this study was shouldered by the individual women. Because of the sensitive nature of the disease, the lack of adequate treatment and information to predict how an individual might respond to the virus, and the minimization of the disease by HCPs, women in the study were essentially left on their own to struggle with the work of learning and maintaining the process of managing fear.

Phases of Managing Fear

The phases of managing the fear trajectory are controlling information, controlling herpes and regaining control. The phases occur and recur over time depending upon what is happening in the lives of the women. The phases do not necessarily occur in a linear fashion. They may occur simultaneously with one phase receiving more attention than another based on factors mediating the fear trajectory at a particular moment in time. Each of the three phases are defined below. Identified properties of the phases are supported with examples from the data.

Controlling Information

Genital herpes is an incurable, sexually transmitted, stigmatized disease that threatened women's physical and social well being. The women in this study faced the task of controlling information to decrease their fear. They controlled information through the sub-processes of: selective disclosing, distancing, and selectively choosing information. Through selective disclosing and distancing, the women worked to control who, what, when, where and how of dialogues pertaining to genital herpes. Through selectively choosing information, they controlled the nature and amount of factual and personal information they received concerning GHSV.

Selective disclosing. As described in chapter 5, fear of disclosure emerged as one of three major types of fear. All women in the study attempted to control disclosure of their genital herpes through a process of selective disclosure. Selective disclosure occurred when an individual woman voluntarily chose the time and conditions under which her diagnosis was made known to or kept secret from a particular person or group. The women viewed decisions to disclose or not disclose genital herpes as a protective stance. They made disclosure decisions

following a calculated weighing of the considerable risks and benefits of disclosing to others the fact they had genital herpes.

Disclosing to sexual partners. The women described rejection and loss of relationship as the major negative consequences of disclosing genital herpes to sexual partners. Fourteen (14) of the women feared their present relationship would end or that men would not want to enter into a relationship with them if they disclosed they had genital herpes. They were concerned that the stigma associated with genital herpes meant that they would be perceived by potential partners as sexually undesirable. For some of the women, the fear of disclosure was based on anticipation of what might happen. One woman who was afraid of rejection asked the following questions.

Who is going to want me? Who is going to want someone who has genital herpes?

Women who had lived longer with genital herpes and who had experienced rejection and/or the loss of relationships following disclosure were guarded.

When I started to tell him I was worried. I never practiced, I mean this was the second time I'd done it [disclosed herpes to potential lover]. I expected him to freak out like the first one I told and he was like 'Oh God, I thought you were gonna say you have AIDS'.

So he was very relieved. He's like going from thinking AIDS to herpes. Herpes is more livable.

Women feared disclosing genital herpes to a sexual partner would result in a change in the relationship. For example, one woman monitored her relationship to determine if the disclosure had "changed things". She described a loss of intimacy immediately following telling her partner about genital herpes.

It's been a week since I told him, not even a week, a few days and he doesn't seem to touch me as much as he did or wanted to. Right now we are both very busy, he's moving into a house and I'm looking for a job and you know stuff like that. I don't know if life is just causing that little distance or if it's the herpes.

The term genital herpes was difficult for most of the women in the study to use in everyday conversations. Using the term genital herpes reminded the women they had an incurable, contagious disease and they didn't want to explicitly remind their partners that they were not "normal". Euphemisms were a common strategy used by the women to disclose genital herpes to new partners and to disclose recurrences in established relationships. Euphemisms are inoffensive terms substituted for terms considered offensively explicit (Morris, 1981). The women used a number of indirect, less offensive terms to replace

the term "genital herpes". Examples of these terms used throughout the interviews were: outbreak, bump, blisters, sore, rising, broken out, knot, infection, boo boo, ulcer and marks. One participant explained being more comfortable using a euphemism in place of genital herpes:

I don't like to say I have herpes. It sounds so awful. When I first told him I used the H word. But now I just say I have a little sore spot. He knows that means I can't have sex. I don't know, it's just easier to say it that way.

The women viewed disclosure of genital herpes as inviting a potential social death sentence, the end of being able to live a normal life. The conditions under which women chose not to disclose, or to disclose genital herpes were varied and concerned protecting self and protecting others.

Keeping secrets to protect self. Women in the study spoke often of not wanting others to know they had genital herpes. They worked hard to keep their diagnosis a secret. Keeping secrets about having genital herpes or choosing not to disclose, was seen by the women as intentional deception.

Intentional deception can occur through gesture, through disguise, by means of action or inaction, even through silence (Bok, 1979). Women in the study often used

intentional deception for self-defense, to prevent others from thinking badly of them, or to encourage potential partners to enter into sexual relationships they might not otherwise enter into or enter into cautiously (Bok, 1979). Sexual deception "...affect[s] the estimates made of risks and benefits" (Bok, 1979, p.21) of entering into a sexual relationship. The strategy of intentional deception most often used by women in the study was silence. For example, one woman described being silent about having herpes as a strategy to protect herself from the emotional pain of rejection:

Sexual history never came up. We had sex with a condom. I wasn't ever going to tell him. I just wasn't up for rejection. A month before I had gotten rejected really bad because before I did anything [sexual] I did the right thing, I said something [disclosed herpes].

Choosing not to disclose genital herpes misleads the partner even if sexual history is not openly discussed. However, sexual deception is sometimes seen as a strategy for survival in a corrupt society in the context of believing that everybody lies (Bok, 1979). Most of the women in the study believed that all men lie about their sexual history. Therefore, women in the study weighed the benefits and risks of disclosing genital herpes in a

context of existing, widespread sexual deception. When asked if she discussed sexual history with her partners one participant replied as follows.

Why ask them [men] about it [sexual history]? You don't think they're going to tell you the truth do you? Girl, you're just kidding yourself. They are not going to say anything that might keep you from getting together with them. Asking them is a waste of time. You just end up embarrassing yourself 'cause they all lie.

None of the participants reported discussing sexual history with their sexual partners before being diagnosed with genital herpes. Most of the women believed they contracted genital herpes from partners who intentionally deceived them.

I think he knew, and with me being as young as I was, he should have let me know. Let me deal with it.

He basically lied to me. He never said he had anything. I thought I could trust him
He seemed to really care about me.

Only one participant believed her sexual partner did not know he had genital herpes. She was in a steady relationship of eight months at the time of her primary outbreak. After being diagnosed she "made" her boyfriend get "checked out" to verify if he had genital herpes.

I made him go get checked out. He had it [herpes] and didn't know. We found out about it together.

Using silence as a strategy of protecting self took a toll on the social well being of the women. The women who chose this strategy had to suffer alone without their usual forms of social support.

It's not easy holding it in. Sometimes I want to tell them [boyfriend, friends & family] 'cause it might help me feel better, but I don't want them to really know.

Sometimes I want to talk, but nobody want(s) to talk to me. I stay by myself to think. I don't tell nobody.

Disclosing to protect self. Disclosing to a trusted other was used as a means of balancing the isolating effects of silence. Many of the women had at least one person they felt they could talk to about their disease and recurrences. Having a confidant protected them against feeling alone in the world as they struggled to manage fear.

I only have one real close friend so that's the only person I talk to about it. It helps me to talk sometimes like when I'm having a breakout. It helps me to think someone knows and cares I'm in pain, that I don't have to suffer through this alone.

I can talk with my mom. She prays for me. She gets a lot of strength from her religious beliefs.

I told my girlfriends I had it [herpes]. They're like 'you do?' I can call them whenever I'm hurting real bad.

Two of the women described using disclosure to partners as an act of protecting self. Disclosing to potential partners protected them against later accusations. In response to hearing other women in the study had chosen not to disclose to their partners one participant said:

I just tell [partners]. That way if they come back to me and say they got herpes I can say you were warned. I told you. If they don't want to be with me because I told them, well fuck 'em!

Disclosing to protect others. Protecting others was a strong theme throughout the data. Genital herpes had inflicted such horrible physical and emotional pain on the women in the study that they wanted to protect others from experiencing the same harm. The women selected to both disclose and to remain silent as strategies to protect others.

As discussed earlier, fear of passing herpes on emerged as one of three major types of fear in the study. For the women who were afraid of passing it on to sexual partners, disclosure was an important strategy. Some of the women felt they owed sexual partners the truth. For this group of women, sexual contact was a condition for disclosure. They believed in disclosing genital herpes

prior to having sexual contact with any partner as a means of protecting the partner.

People [sexual partners] have to be told. It has to so you don't give it to nobody else. It's not a pleasant thing to have. It's not pleasant at all.

You've got to let them decide for themselves if it's a risk they are willing to take. I wish I had been given a choice.

Other women saw caring as a necessary condition of disclosure. Caring was expressed as caring about the person.

If I really liked them I would tell. Because, I wouldn't want them to get it. And they would be really mad at you and never talk to you again.

Everybody knows diseases are out there. I wouldn't tell unless I really liked the guy.

I told one guy, an ex-boyfriend of mine. I told him because I care about him. I told him I really care about him and I wanted the relationship to go somewhere and he said he really cared about me.

Caring was also expressed as caring about the potential of the relationship.

That was like just a fling, I didn't think it was going to last. I didn't think it would go that far so there was no reason for him to know.

We had sex with a condom. This relationship, wasn't supposed to go anywhere, it was just supposed to be like a friend thing, and then it got to be more than that, but I was still planning on keeping it on a friend level and I wasn't ever going to tell him.

Disclosing was also used as strategy to protect family and friends. Several participants disclosed their experience with contracting and living with genital herpes as a protective warning to family members and friends. One woman planned to disclose to her daughter to protect her from future harm.

I tell you one thing, I will tell my daughter when she is like ten years old. I will make sure that she knows better, and I will make sure she is scared to death. You know, not scared to death to have sex but scared to have sex with a bunch of people. I mean I still don't think it [sex] is wrong, but I think people should stop and think, you know, is it worth a one night stand?

Other participants warned their girlfriends and sisters to be careful.

My friends tell me about their boyfriends I always say 'you better be careful'. I have told my sisters to use condoms, and they notice that I am like that, and they know why and they ask me 'why do you cares much? It's not you.' I always told them that you think it's not going to be you and when it turns out to be you, well then you realize. I thought I would never [get anything], I thought I was too good and I thought I'm not from the streets, it would never happen to me, and it did.

Disclosure to protect others was viewed as a gift by the participants because it was given at potentially great personal cost to them. One participant was upset that her gift of warning through disclosure was not heeded.

The only reason I told my best friend was because I wanted her to see what happens when you don't wear a condom, cause she doesn't. I don't think it mattered. I think I pretty much embarrassed myself instead for no reason. I don't know what I expected from her, I mean she was sympathetic to me when I went through that bad ordeal [primary herpes outbreak], but she has slept with so many other people nonchalantly. I would never wish this on anybody, but to share this with someone and for them to nonchalantly want to screw everybody else in the world is horrible.

Revenge motivated one participant to "out" her former boyfriend. The woman disclosed her former boyfriend had genital herpes to her sister, cousins, and friends. She wanted people that knew him to be aware he had genital herpes. She was angry that he hadn't disclosed his history to her and she believed he wouldn't tell others.

I'm still angry with him cause I have to live with this my whole life too. He's probably going around not telling anybody. I told my cousin and them, but I don't be around where he be. He's like in Miami and stuff so I don't go to Miami. So none of my friends know him except my cousin and my sister.

Keeping secrets to protect others. Two of the women in the study used silence as a strategy of keeping secrets to protect others. They were afraid that the person who gave them genital herpes was at risk of retaliation from family members or a current boyfriend. One participant kept the source of genital herpes a secret from her mother

because she wanted to protect both her mother and the former boyfriend from harm.

My mom was there the day the day I found out. She wanted to kill him. She was like, well I told you about that and like who was it? I didn't even tell her who it was. I know her. I was afraid she would go acting silly. I would have been glad if she would have went and said something to the boy but I wanted to do it myself and I did. I didn't want her getting in no trouble.

Another participant contracted genital herpes after being "raped" by a former sexual partner. She did not disclose the name of the person who raped her to her current boyfriend because she was afraid he would want to beat him up.

I told him I was raped by someone I knew. He wanted me to tell him who it was. I told him it didn't matter because I afraid he would want to go and beat him up or something.

When asked why she would want to protect a man who raped her, the woman replied:

Well, I broke up with him and he came over to my house one night and he was drunk and drugged and he raped me. He doesn't remember, because I faced him about it [the rape] and he doesn't remember. He remembers coming over, but he doesn't remember anything else.

Forced disclosure and lovers. The antithesis of selective disclosing was forced disclosure. Forced disclosure refers to disclosures that are imposed, or produced under strain. Some of the women in the study felt

forced to disclose their history to sexual partners out of self-defense. They were afraid of what might happen if the partner found out later that by remaining silent, they had intentionally deceived them about having herpes.

If you don't tell them [sexual partners] and they find out about it later, they might get real mad at you.

Reactivation of the virus placed one of the women in a situation in which she felt forced to disclose she had genital herpes. Reactivation limited her sexual activity and she felt forced to explain her sexual unavailability to her partner. Because the participant already had sex with her partner without disclosing genital herpes, she scripted a defensive disclosure. The defensive disclosure enabled the woman to tell the partner she had genital herpes without risking accusations of deception and decreased the risk of losing the relationship.

I had sex with him and I didn't tell him and then two days later I broke out and I got scared. I didn't tell him until a week later that I had broken out cause he wanted to have sex again and I'm like I can't and he's like you know hurt and he's like 'Why?'. He thought I had lost interest in him. So I had to tell him. I told him it [herpes] was because of stress and stuff and that it was my first breakout. I didn't want him to know I didn't tell him before. I didn't want him to think of me like that.

Forced disclosure and HCPS. Forced disclosures also occurred in health care settings. One participant described feeling out of control of who was told she had genital herpes during the critical event of being diagnosed.

I was told with three or four people in and out of my room. I was told by a woman who didn't know what she was doing and had to have a second opinion. Her first reaction was. 'Well I don't know what it is, I'm going to call somebody in'. Well that right there scares anybody. And you know she was with the doctor and she's like I think that's herpes but I'm not sure. The doctors there you know didn't say anything for a long time and meanwhile you're sitting there and you're exposed and there is no caring. To them it's just another lesion, another piece of meat.

Due to the possibility of transmitting GHSV during delivery or in vitro, several of the participants who were pregnant at the time of the interview described feeling forced to disclose they had genital herpes to their obstetricians. They felt they had to put the baby's well being above their own.

I wouldn't tell anybody if I didn't have to. But I'm pregnant. I kinda have to tell him [obstetrician]. I didn't want to [tell] but I did.

Consequences of disclosure. Women in the study were aware others might not keep their secret was a possible consequence of disclosure. Telling a friend, family member, or lover about genital herpes meant risking they

might tell someone else. Therefore, telling anyone about genital herpes increased the risk of others knowing.

You have to be careful who you tell. Even if you're careful it might get out. It's going to get out and once it's out then you're definitely blacklisted I think.

One participant was in the hospital for a kidney problem that occurred during her pregnancy. As we began the interview, she asked me to stop the interview anytime a particular nurses aide came into the room and to begin talking to her about something else. The participant was afraid that if the aide knew her diagnosis of genital herpes, boyfriend's cousin, the aide would tell others in the family and in the community.

That's my boyfriend's cousin. I don't want her to know I have herpes. I know her, she would spread it all over town. You have to be careful who knows.

One participant had experienced having a confidence betrayed. She had a heightened awareness of how fragile the secret was once she had disclosed her diagnosis to someone else.

I'm the type of person that could probably have a secret and not tell anybody, but I told her [roommate] because she was living with me and she was going to find out something was wrong with me and I wasn't talking. But inside my heart, her ex boyfriend used to have it [herpes] and she was with him five years and never got it. She told me a long time ago he had

it and I'm just afraid that she is going to trust somebody and she is going to tell them I have it.

Disclosure by others is especially problematic in small communities. One ARNP in public health unit B, described the common phenomena of women learning about genital herpes exposure "through the grapevine".

I really don't think a lot of women will discuss it [herpes] with other subsequent partners. I think a lot of people hear it through the grapevine, that oh well I heard it from so and so that he had a partner with herpes. I don't think the partner directly tells the new partner, I think people just hear it through the grapevine. They tell us when they come in that they heard about it from someone else. They don't really do anything about it. We counsel them on safe sexual behavior, but I don't think they confront their partner at that time.

For women in this community, disclosing genital herpes to a sexual partner, friend, or family member means risking becoming part of the community information network known as the grapevine. The reliance on the grapevine to access information about the sexual history of partners has the potential to impact the patient-provider relationship. Providers, to be trusted, must be seen as someone who is outside the grapevine. One ARNP described her social standing as a safe outsider.

I'm not from here and I'm not from Florida so people tend to trust me a little bit because I don't live in the community where a lot of our patients come from. There is a big grapevine in the community, but I don't

live in the community so I think people see me as someone they can trust.

Distancing. Social distancing enabled women in the study to control information by decreasing close contact with others. Social distancing reduced situations in which there was a need to consider disclosing to others. Reducing the number of people that knew they had herpes also limited the risk of forced disclosures. However, distancing also limited the participant's opportunities to live a normal life. The most common distancing strategy was avoiding sexual relationships.

I figure if I don't bring it upon myself, if I just avoid the whole thing like not being with anyone and not having to have a relationship and say anything and just avoiding all of that. It's safer.

I'm at the point now where I don't even want to have a relationship. I don't know if I ever will. I can't even think about that now.

I just decided to dedicate myself to raising my child and just living with it [herpes]. I'm not going to get remarried, I'm not going to. It's not going to happen for me, I just really believe that. Maybe I'm wrong or I guess it's going to have to prove me wrong. I'm not going to live a normal life. I just can't. How could I?

I usually just say I'm not ready to date right now, I just came out of a relationship. In other words I lie. You know I just think my life is going to be lonely as far as having a partner is concerned. I just think that's it for me.

Participants also distanced themselves from family and friends. In describing how herpes had impacted her life, one participant stated the following.

I just don't go out with my friends as much anymore. Herpes has made me more serious. My friends think I just don't know how to have fun anymore. Even my sister thinks I'm no fun anymore.

In an extreme case of distancing, one participant would not allow her boyfriend to physically touch her or let her children sit on her lap during her outbreaks out of fear they would "get" the virus.

When I'm home I don't like them [children] sitting on my lap, nothin like that. It's killing me, I don't want my children to get nothing. If I have the bump I don't like him [boyfriend] touch me. I feel uncomfortable. I don't want him near.

Selectively choosing information. Selectively choosing information was a process through which participants controlled the nature and amount of factual and personal information they received about genital herpes. Controlling information about genital herpes enabled women in the study to reduce their fear levels. Selectively choosing information included both accessing and avoiding information, depending upon the individual participant and factors mediating the fear trajectory at a particular moment in time. Accessing information included

strategies such as fighting for information, talking with friends, and reading.

Fighting for information. HCPs provided participants with initial information about GHSV at the time of diagnosis. At this time, the women were faced with processing complex information about their diagnosis, prognosis, and treatment options. This information was usually provided orally by HCPs in clinic or private office settings. Because of the life altering ramifications of hearing they had an incurable, communicable, sexually transmitted disease, the women often not always able to listen attentively immediately following their diagnosis. As a result, many of them had unanswered questions and/or left with only partial information with which to manage their fear trajectories.

I was in shock. All I could remember was the doctor saying 'It's herpes, there is no cure'. The sores will go away on their own and that it was contagious.

All participants accessed information from HCPs. However, experience with and access to HCPs as information resources varied. The women who had ongoing, trusting relationships with their providers reported more positive experiences both with the quality of information provided and with access to additional information.

I get my information through here [HCP's office]. She's been perfect, just excellent. She has given me a lot of information. She tries to answer all my questions. She told me to call if I have more questions.

However, being in an ongoing relationship with a HCP did not necessarily lead to a positive experience for the women. The temporal nature of the HCP patient relationship was not sufficient to create an environment in which the women felt their information needs were being met. Some of the women reported fighting to get their questions and concerns heard and addressed despite being in ongoing relationships.

He [HCP] doesn't take my questions seriously. He tells me not to worry about it [passing herpes to the baby]. He says he'll worry about me and the baby. But not knowing stresses me out.

Doctors don't like to spend the time, you know, they are on a tight schedule. They book patients every 10 to 15 minutes. They need to know that they need to take more time with the patients because they have to understand that at first it can come as a big surprise. They need to thoroughly explain that you are going to be OK. I really didn't get that at first.

The health care delivery systems used by some of the women in the study did not foster the establishment of ongoing relationships between patient and HCP. In these instances, such as public health unit A, participants essentially saw a stranger each time they accessed health care. It was

difficult in these settings to establish provider-patient relationships in which trust was developed and relevant problems could be openly discussed. Participants attending a public health STD clinic described their experiences in the following way.

I had a lot of questions about sex. I don't think he [HCP] was comfortable talking about it or maybe he didn't have time. But he just said don't have sex during an outbreak and went on to something else.

I didn't really feel comfortable talking with her [HCP]. The only thing she knows about me is I have herpes.

The economic status of the participants made it difficult for them to change providers if they were not satisfied with the quality of information received. They used additional strategies to supplement information they received from their HCP.

Not surprisingly, several women volunteered to participate in this study as a means of accessing information. In response to how she felt about participating in the study, one participant replied:

I just figured I can get information and feedback. You know I am interested in finding out more, but I am not willing to pick up the phone and say 'this is what I have and I want to know more about it'. I knew I would get to talk with you in person.

In addition, two women called in response to posters advertising the study to get information about genital herpes but chose not to participate in the study. The women were not comfortable discussing their personal stories but used the researcher as a resource strategy.

Talking with friends. Genital herpes is highly stigmatized and not generally talked about openly, most of the participants did not know anyone else with genital herpes who might have been a useful source of information or support. Only one participant reported talking to a friend as a strategy for obtaining information. Because the participants' friend also had genital herpes and knew what she had been going through, the participant found it helpful to share stories about the experience of living with genital herpes helpful.

I have a friend from middle school. We grew up together. I never thought she would have herpes. Because she told me it was like OK, I'm going to tell her. But she lives really far away and we don't communicate as much but when we do it [herpes] always comes up. We make a joke between us. It's helpful and it does help and we can tell each other our stories of what we went through and how it was like for her and what she felt and the same for me. But it's just we don't talk all the time. This has happened two or three times when we talked. It's helpful because she must really know what I'm going through because she is going through the same thing. I haven't told anybody else. I just can't.

Reading for information. In addition to talking with HCPs, participants also used reading as a strategy to access information. Anticipating information needs of patients, HCPs frequently backed up their teaching efforts with printed materials.

I've learned about it [herpes] through going to the health department and reading pamphlets on things like chlamydia. She [HCP] gave me some pamphlets and stuff.

As reported earlier, educational materials are frequently written beyond the reading level of many low income women. The educational level of the participants in this study ranged from no formal schooling to four years of college. The average educational level was 11.6 years. Reading levels are estimated to be 3-4 years below an individual's stated educational level (Cimprich, 1992). Therefore the average reading level for this sample fell approximately between the 7th and 8th grade. Gordon & Sherrod (1996) reported commercial and generic GHSV educational materials were written between the 8th and 9th grade reading levels. The reading level of printed materials decreased the access some of the low income women had to information about herpes.

The educational materials provided by HCPs reflected a public health focus of preventing transmission and did not address all of the information needs of the participants.

The pamphlets they [HCPs] give you just tell you what it is and how it's treated. They don't tell you how to live now that you've got this [herpes].

Therefore, some of the women in the study sought information independent of their HCPs from sources such as the public library and family members.

My mother had gotten a bunch of books, just pregnancy books, from one of her friends. I already had books here before I found out [about herpes]. In the books you can look in the index and it tells you. I just started looking under H, you know, for herpes and sure enough it had a couple of pages in every book. So I got to see, you know, different views in all the different books and everything. It said about the same thing in almost all of them.

I do a lot of follow up. I do a lot of reading. The doctors don't always keep up.

I read in a book when I was pregnant they the doctors saying they have a study in genital herpes and that protein is one of the amino acids that helps to fight herpes and of course you can't always believe what you read, but I thought what choice do I have? I might as well try it and I found that it worked [reduced frequency and severity of outbreaks].

Four (4) of the women in the study were pregnant.

Three (3) of the pregnant women expressed needing increased information to help them manage their fear trajectories.

Reading became a powerful tool that allowed participants to

overcome what they perceived as a conspiracy of silence on the part of HCPs.

Really they didn't tell me too much. I did a lot of reading on my own. I did my own research so I could ask questions because nobody was telling me anything.

I really had concerns about the baby and I wasn't getting straight answers. I took it upon myself to find out facts and then when I approached them with facts you know, they commented 'I see you've been doing your own research' and then they had to talk to me about it.

One participant was concerned that being seen at a free clinic might jeopardize the quality of care she received. She verified information she received through books and her HCP by calling a research center.

They see women with all kinds of disease here. I don't think they take us seriously. They see a lot of vaginal diseases and stuff. I just want to make sure I get treated right. Most of my information I got from books and then I just call the research center to verify a lot of stuff.

Despite efforts at obtaining information, women were frustrated with the lack of knowledge available to adequately address their questions and concerns.

Every book tells you something different. For instance you get in contact with an open sore and seven days later you break out. That's not necessarily true. The books are not accurate. I can't find anything in the library on that particular subject that goes into it in any depth.

One woman described her frustration with the inadequacy of available information as dancing in the dark.

The doctors can't help you much. I wish there was a book written on absolutely every aspect of a person's life that has to deal with it [herpes]. You know I mean, telling someone, getting a new relationship, having children, having sex, how do you know it's coming. You know, I mean just a varied, detailed book on how you are supposed to live your life now. Right now I feel like I'm dancing in the dark, ya know?

Information and fear. Accessing information about genital herpes did not inherently decrease fear levels. Sometimes knowing more about genital herpes caused an increase in fear for some of the women. For example, two of the participants described having a greater fear of transmission after learning more about how the herpes virus is transmitted.

I knew it [herpes] never went away, I didn't know what it was. I thought it was like a really bad case of road rash. I didn't know anything. As far as I knew any and every STD can be stopped by a condom. I mean AIDS will kill you, but herpes anybody can get. Now I know no protection is for sure with herpes.

It's [herpes] the worst because you can be careful and still get it. I mean a guy can wear a condom but he can still get it on his scrotum or the guy could have it on his scrotum and give to the girl on her buttocks. It's just not fair! It's enough to make you not want to have sex ever again. Even oral sex isn't safe.

Four of the participants in the study avoided information as a strategy to manage fear. Actively seeking knowledge about herpes caused them to think about having the disease. Consciously remembering they had the disease and that it was incurable caused them to be afraid. For these women, avoiding information allowed them to avoid increasing their overall fear levels and increased their ability to forget they had the disease.

I don't go looking for it [information]. The more I know the more I think about it and that makes me scared.

I don't talk to nobody about it, not even my doctor. There is nothing I can do about it so I don't want to know. I just want to forget about it.

The more you know the more you realize how really horrible this disease is. Unless they find a cure or a medication that really works, I don't want hear about it!

I haven't been looking for information about it. Knowing makes me think more. I get depressed. The more I know the more I don't talk to anybody. The more I have to be by myself.

As the women increased their knowledge of genital herpes, disclosing to sexual partners became more complicated. Women in the study felt an obligation to disclose what they knew.

I had to tell him you could get this [herpes] in other areas. Now he feels at risk every time he touches me. He's very worried about getting it on his hands, on

his face. Who wouldn't be? I don't know anything about how to relieve him of the way he feels. I don't want him not to want to touch me because of that [herpes].

I didn't know you could pass this when you didn't have an outbreak. I didn't intentionally give it to him. Now I would have to tell someone that is a possibility.

I'm not gonna lie, you know? That's number one. I've read so many books on it since then [being diagnosed]. That's another reason why I feel that my life is destroyed, because now I would have to tell somebody all that I know. After that I'm not going to see them again.

Withholding known information was viewed by participants as a form of deception. Therefore, the more the women knew about herpes the more information they felt obligated to disclose to potential lovers.

I couldn't lie to the guy. He asked me and I had to tell him how bad it was for me, you know? Now he is afraid.

Controlling Herpes

The work of controlling herpes was based on the women's desire to reduce the fear of pain and of passing it on by recognizing when they were most contagious and by controlling the number and/or severity of outbreaks as best they could. Participants attempted to control herpes by the sub processes of body listening, reading the signs, recognizing triggers, and tending to herpes.

Body listening. Strategies aimed at controlling herpes required that the women know their body's unique patterns of response to the virus. Learning body responses to the virus was based on an awareness of and attention to an understanding and interpretation of one's body. Price (1993) called this phenomenon has been called body listening. Consistent with the participants in Price's earlier study, body listening was described by the women in this study as a learned phenomenon. Women in the study described listening to their bodies as paying attention, knowing when something is not right, and watching for signs and symptoms of genital herpes. One participant described not paying attention to her body prior to the diagnosis of genital herpes and how important knowing her body had become.

I never paid too much attention to what was going on with my body, now I have to know. I have to pay attention, or I'll pay later.

The women described the work of body listening as a continuous, day-to-day activity in which they listened for personal patterns that would predict outbreaks.

I am basically that way anyway so I am constantly aware of what is going on with my body. You have to be [with herpes].

You've got to watch for the signs [of herpes] all the time, every day because you never know when you're going to get it [herpes] or what is going to cause it.

I am always on the edge basically to make sure I don't have an outbreak. It's basically way beyond my control.

Women in the study had to balance paying close attention to their body without letting genital herpes dominate their life. Paying too much attention to knowing their body might interfere with other aspects of life. Too little attention left the women feeling outbreaks came out of the blue, increased uncertainty, and increased the perception of feeling out of control of their lives.

Reading the signs. Knowing the body through body listening allowed the women to construct a new understanding of their bodies. Knowing when a herpes outbreak was coming required being able to read the signs of an impending outbreak. Prodromal signs were early indicators that the virus had reactivated and found it's way to the surface of the skin or mucosa. People with genital herpes report a variety of prodromal signs. However, HCPs are not able to predict what the signs will be for a particular individual. While women in the study varied in their ability to articulate warning signs, over time they learned when an outbreak was eminent. Early

warning signs or prodrome included vague feelings, headaches, itching, burning, tingling and/or pain at the site of previous herpetic lesions, genital area, buttocks and/or legs.

I can't really describe the feeling, but I know. You just know.

It starts to get sore down there and you know it's [herpes] coming.

You can tell when it's coming on from the itching or the burning sensation you get when you go to the bathroom or from just wiping normal you can tell that it's there.

Some times it will come on and I know it a week before it's coming. Because it starts, I start, with a tingling in my toes. It starts like a very numb feeling gradually working all the way up to my leg. The way I could describe it is if you have a nerve, a pinched nerve, and my whole leg will start getting numb and eventually it will work up, usually only in one leg. Just the left one. That's how I will know. It starts back up down my toes and comes all the way to the back of my leg and then to my bottom and um it's like that for days and then I get an ache in my vaginal area. Sometimes it's really painful. And that's when I know it coming on and it will come out. I don't get any outbreaks on my right side. It's strange but I don't know why.

I always get a headache, this special headache that I only get when I'm going to have an outbreak. That's how I know it's coming.

It feels like a bump at first, and then it breaks and then it feels tender. And it's just like a cold sore only it's down there.

I can feel like burning, and it itches a lot and it's a little swollen and it's red. That's about it.

For the most part, women in the study struggled to learn how to read the signs on their own. Through body listening, they noticed what they were feeling before an outbreak of genital herpes. Over time they learned to trust their knowing. However, two of the participants sought verification of their interpretation of the signs through HCPs.

I was taking a shower last night and it burned, and I went in today and they said it had just started. They were not big and they don't have puss in them yet, they are just marks.

I go to the doctor every time I think I have it [herpes]. I want to know for sure when I have it and when it's gone.

Being able to read the signs decreased some of the uncertainty associated with genital herpes. Knowing when an outbreak was eminent enabled the women to reflect on what was happening in their lives and to take steps to reduce the severity of the outbreaks:

When I feel it's coming I just stop and try and figure out what's going on that's stressing me out and I just stop it.

When I know it's [herpes] coming I take a pill right away. Sometimes I can stop it [outbreak] altogether.

I've noticed that now I know when I'm going to get it [herpes] and if I take care of it really quickly, it goes away like the next day or the day after.

I try not to think about it. You know, I kinda of keep my mind off of it.

They try to tend to reduce the chance of passing the virus to others.

When you first get this [herpes] you never know when it's coming. You can't plan. Now I don't worry as much about passing it to someone else. When I feel a tingle down there I know it's coming and I don't have sex until it's gone.

Outbreaks cannot be predicted with certainty from a strictly scientific point of view (Ebel, 1998). Despite feeling able to recognize the signs, women in the study worried about not knowing when they were having an outbreak.

They [HCPs] tell me that sometimes you can't tell when you're having an outbreak. I worry about that especially with the baby now that I'm pregnant.

Sometimes I have little outbreaks. I hardly know they are there. Those are the ones I really worry about. I might miss one.

Not being able to read the signs increased the uncertainty of genital herpes. Not knowing when an outbreak was coming also increased the fear and risk of passing it on.

Recognizing triggers. In addition to reading the signs, part of knowing the body is recognizing triggers. Triggers are defined as any biological or behavioral event that influences latent HSV to reactivate (Ebel, 1998,

p.206). Over time, women in the study were able to identify certain physical events, foods, or thoughts that they associated with outbreaks. Emotional stress was the most common trigger identified by women in the study.

I've learned, I didn't know earlier, but I know what I have learned. Stress is my biggest factor. Situations that I feel I have no control over and are very stressful to me and I think I internalize those situations and my body reacts to stress by having outbreaks. For example, my husband at the time signed my son up for scouts and volunteered to be a leader without consulting me in the least. Suddenly every Monday night our home had to be prepared for a Boy Scout meeting and he didn't have time to organize the events. And so I had to fit it into my schedule. I was being the good wife, running to the craft store and making sure we had lemonade and cookies, that we couldn't afford, and was never even consulted! I always had a thorn in my side about scouting. It wasn't a surprise to have an outbreak after a particularly stressful Monday.

Anything that puts the body under stress can bring it on. It could be work related, it could be a relationship, it could be something that upsets you.

When I try to live my life without too much stress or whatever and take time out for myself and do stuff for me and make myself happy, make me and the baby first I don't have it [herpes outbreaks]

When I get stressed out that's when they [herpes blisters] usually come up. I don't know it's hard to explain. Like when I became pregnant and I knew if I had this [herpes] the doctor said if I had it when I was ready to deliver I'd have to have a cesarean. That worried me because I didn't want to have a cesarean. So that kinda stressed me out and I had an outbreak.

For the participant who was HIV positive, stressors included seeing a new doctor and changes in her medication regime.

Seeing a new doctor or starting a new medication will sometimes bring it out. Anything that is a change. I guess it causes me stress.

Several types of physical stress were also identified by the women in the study as triggering outbreaks of genital herpes. Physical stressors included fatigue:

I have learned not to fatigue myself, not just physically, but in general to get lots of sleep. I feel travel is a risk to me for this, because you get out of sync with your system um sleeping patterns are different, eating habits are different, the stress of travel, preparing for the trip, what ever you're dealing with when you get there.

menstrual cycle:

I can count on getting an outbreak every time I have my period. It's like a clock. I get my period - I get herpes.

Sometimes my cycle brings it on. I've heard other people say it can be brought on by their cycle.

sexual intercourse:

If I have sex and the person uses a condom and every thing it brings on an outbreak.

It [herpes] has most definitely effected my sex drive. For me sex brings it on, definitely brings it on. When I think of sex I think I'm going to have an outbreak. It doesn't happen all the time but two out of three times it will happen. I have to weigh how important sex is over the risk of an outbreak. With

or without a condom if I have sex I have an outbreak in a couple of days. I can go two or three weeks without an outbreak and if I have intercourse, I have an outbreak. It's something that really wrecks your life, your whole life really.

physical illness:

I just recently had an outbreak and I had bronchitis. Being sick kinda brought it [herpes] on, it was kinda rough being sick and trying to take care of myself too.

exposure to sun:

The sun bothers me. I know if I spend time running around in the sun I am going to get an outbreak. I try to be careful with that, you know, limit how much time I spend in the sun.

and certain dietary elements such as chocolate, caffeine, raisins, beans, oatmeal and Jell-O:

You know one thing I've learned is I can't eat too much chocolate. I think chocolate has a factor in this. I don't know how to make the connection but if I go on a chocolate binge, sometimes before or after my period, I don't know if it's connected with my period or not. I kind of tested and did the chocolate thing no where near my period and too much chocolate seems to effect it. I get the ache in the middle of the night and I think oh no I shouldn't have eaten that big butterfinger this afternoon. So I work at not going overboard on chocolate.

Chocolates bring it on. I guarantee you right now if I wanted to prove it I could eat some chocolate and I would have a outbreak!

I've noticed caffeine can bring it [herpes] on if I have too much. If I start to feel it coming I slow down and back off the coffee.

Certain foods I can't eat because it [herpes] comes on right away. I have to cut all the peanuts in my diet

because it brings it on. Raisins, beans, oatmeal, and Jell-O too, any flavor.

Recognizing triggers enabled the women to develop outbreak control strategies aimed at reducing the number of outbreaks by successfully avoiding triggers. Being able to influence the number or timing of GHSV outbreaks increased the women's overall sense of feeling in control of their lives. While stress could not be avoided entirely, participants described controlling outbreaks through reflecting on what was going on in their lives and initiating stress management strategies on a day-to-day basis.

Whenever I start to feel stressed, like when the baby's daddy upsets me or the kids get on my nerves, I try to calm myself down. Take a walk; take the kids to the park. That usually calms me down. I also only call my ex when the kids need something. I stay away from what I know upsets me.

I try to relax as much as possible. That's the only thing that seems to work. I've eliminated a few people from my life, a few girlfriends. I find that helps [reduce stress] a lot.

I try and stop it [stress]. I always look around and say "What is going on? 'What is stressing me out?' and I stop it and save another time for that and do what ever else I need to not stress myself out and I don't let anyone stress me out.

I take the medication, I get off my leg and I rest. I may go to work at 8:00 in the morning and every thing is fine and by 3:00pm I have that pain in my leg. I will come home from work, I will say I need to leave.

I take my medication and I go to bed. If I do this, I'm usually OK by the next day.

Women who identified food products as outbreak triggers limited the offending products in their diet and incorporated other dietary changes:

I try to drink lots of milk. If I can catch it early enough then that will usually stop it. Certain foods do help, like chicken. I will try to eat the foods I know will stop it, cheese, and dairy products that sort of thing. I read in a pregnancy book that protein, it's the amino acids in protein, that helps to fight herpes. You don't always believe what you read but, I thought well what choice do I have and I might as well try it. And I tried it and found that it works for me. Sometimes it helps if I'm quick enough. Other times there is nothing you can do.

Basically I try to stay healthy. Eat good food, exercise, you know, just take care of me.

Tending to herpes. When outbreaks occurred, women engaged in the work of tending to herpes. As reported earlier, little information was provided through dialogue with HCPs or educational materials that addressed how to tend to herpes. The process of tending to herpes is learned individually through trial and error. Over time, women in the study learned what worked for them. For the women in this study, tending to herpes involved the strategies of cleaning, comforting and self medicating.

Cleaning. All of the women in the study described some form of cleaning ritual. The cleaning rituals varied. Most of the women tended to herpes by washing their hands following contact with the genital area.

Basically, you know, I was just told to make sure you wash your hands all the time, you know, after you go to the bathroom and stuff like that. Stuff that I make sure that I do now. That's really basically all you can do that's all they [HCPs] told me to do.

I'm going to be extremely careful when the baby comes with my hygiene. It is so easy to transmit it. I'm going to wash my hands and make sure if I have an outbreak to be extra careful with the baby. That sort of thing.

I'm conscious now about washing my hands after going to the bathroom. Sometimes you run in the bathroom and you're in such a hurry you're out the door, but now, ever since then, [herpes] I feel like a doctor always washing my hands. Now I'm extra conscious of about it [hand washing] now 'cause I'm afraid.

Three of the participants described obsessive, extreme cleaning rituals that were time consuming and served to socially isolate the participants during outbreaks.

I just stay home during outbreaks. I am really careful. I clean [genital area] all the time. I wash my hands after I clean 'cause I'm scared of getting it on my hands.

When I go to the bathroom, like a regular visit to the bathroom, about two or three times day, I use lots of toilet paper, make sure I wash my hands right away before I touch my eyes, paranoia is huge. When ever I have access to my own bathroom, I have my baby wipes and I just clean, like if I'm not going to take a

shower, you know, 'cause that's kind of a pain, to towel off you're whole body. I just clean down there.

I think I'm dirty. I like to shower a lot, I feel unclean ya know? I like to go to the bathroom and clean myself. Make sure I'm clean and fresh...changes my clothes. I shower and change my underpants four or five times a day. I think I'm gonna do that [clean] all the time.

It's nothing really I can do but rest and I have to bathe constantly, you know, keep myself clean and dry and stuff like that. I don't be feeling right so I have to go bathe because I guess because to me I don't be clean. I bathe all day. I have to bathe at least four sometime five times. But other than that there is nothing I can do. I don't want to be bothered. Mostly I stay by myself. My boyfriend understands, he know not to bother me. He feels that too when he's hurting. He has his days when he don't want to be bothered.

One participant who was HIV positive described extending the cleaning ritual to include washing her toilet and laundry with bleach and water to protect her kids. She was more concerned about transmitting herpes than transmitting HIV.

I wash the toilet with bleach and water after I use it. I want to be on the safe side with the kids. I've never heard of any one getting this [herpes] from the toilet but you have to be careful, probably more careful than you do with HIV. It brings about a change in your life on how you look at personal hygiene. Doing laundry, I add more bleach and things like that. I wash my own clothes and then I wash the kids clothes separate after I've cleaned the machine or something. Just to make sure no bacteria is floating around anywhere.

Comforting. For the women in this study, genital herpes was a very painful disease. As discussed earlier, fear of pain emerged as one of the three main types of fear that left the women feeling out of control of their lives. There was very little information provided to them by their HCPs about how to ease the pain and discomfort they experienced. In a discussion of the difficulties of treating genital herpes, one HCP stated:

We have very little to offer them. I know genital herpes can be extremely painful for some women. We simply don't have anything to tell them. It's nerve pain. It resolves on it's own. I usually recommend they take Tylenol or another over the counter (OTC) pain medication if it [pain] gets bad.

Low income women are left on their own to learn what works for them through trial and error. Women in the study reported using relatively very few comfort strategies. The strategies reported included the use of ice, wearing loose clothing, cutting pubic hair, and rest.

Every now and then I will put ice down there [genital area] or use a cold compress, and it kind of takes away the itch and the burning.

Tight clothes are a problem. Usually just your underwear touching it [herpes] causes pain. It's a very painful disease. I always try to wear something loose so it won't agitate the herpes. Tight fitting clothes irritate the bumps by rubbing against it. It causes friction and it causes them to burst open and then you get a burning sensation and an aching pain

and you hate to get up and go to the bathroom and pee 'cause you know it's going to hurt.

I cut the pubic hairs where the out-breaks are to keep them from getting tangled up and pulling. Pulling can cause them [blisters] to leak. Once they leak you have burning and severe pain especially when urine gets on them. It's like putting salt on an open sore.

In addition to the strategies listed above, avoiding sex during outbreaks was seen by most of the women in the study as a comfort strategy.

If I feel like, if I have an outbreak I definitely won't have sex.

I think sex during an outbreak would hurt so I don't do it. My boyfriend understands. He knows I'm in pain. He's the one that gave it to me so he doesn't say too much.

Self Medicating. Most of the women in the study tended to herpes by using pain and/or anti-viral medication during outbreaks of genital herpes. The women made decisions about when to start a medication, how often to take it, and in some cases, what medication to take. The women self medicated themselves on the basis of access to HCPs, previous experience with the efficacy of medications in the past, and economic issues.

I take the oral medication mostly. I take one or two whenever I have an outbreak. I tried the creme once. The cream really doesn't do very much for me but if I take the oral medication it works pretty well for me. I take it right away before it [outbreak] gets worse.

The cream [Zovirax] kinda of settles it down. You have to keep putting it on 'cause it wears off.

As one participant pointed out, anti-viral medications do not relieve pain. Without input from her HCP, she chose to incorporate a pain reliever with her anti-viral therapy.

When I get that ache I have found that aspirin therapy to be the most helpful in combination with the Zovirax pills. Not any of the other things, pure aspirin. I megadose aspirin, two aspirin four times a day takes away the pain until the Zovirax works. Zorvirax really doesn't help the pain, it stops the virus.

Anti-viral therapy works to significantly reduce the severity and duration of recurrences. If anti-viral treatment is not started before the appearance of lesions, the duration of the recurrence is not reduced (Management of Herpes Virus Infection, 1996). For low income women, limited access to HCPs also limits their access to anti-viral therapy.

I try to go to the clinic as soon as I know it's [herpes] coming. Sometimes I have to wait a couple of days for the clinic to open. But I never put off going. Like I never wait a week or so. I've learned to get right in.

Anti-viral therapy is expensive. For low income women access to medication can be problematic if they do not receive medication directly from their provider. Several of the women in the study worried about not having enough

money to access medications. Inability to access medication increased their fear of pain:

I would have those pills at any cost. I would not go without this medication. I would avoid, I mean I would not pay the electric bill, if I had to pay the same amount for the pills. I would deal with the electric bill later. I know I have to have them. I keep them on hand always. I never let my prescription run out. I used to carry them with me all the time. Now I know the medicine cabinet is close enough.

The biggest thing is oh my God the Zovirax is so expensive! Sometimes I have to go for days without it because I couldn't afford it. It's a problem to have to have it and not be able to get it. To know you can't get access to it. They need to have it where you can go and get it and I don't know, there has to be a better way.

One participant described rationing her anti-viral medication in an effort make the medication last as long as possible:

I only take one pill when I have an outbreak because they are so expensive. I use to get 'em free so like I stocked up on them. Now it would be a problem [to get the pills] because they are like \$50 a bottle.

Suppressive therapy is recommended for persons who have frequent or severe recurrences, prodromes too brief to permit the initiation of episodic therapy, psychological distress from recurrences; or immuno-suppression (Tyning & Sadvosky, Infections, 1996). It is interesting to note that only the HIV+ participant was placed on suppressive

therapy. The rest of the women were placed on episodic therapy.

Regaining Control

Regaining control of the fear trajectory was a slow process of forgiving and moving on. Through forgiving and moving on participants regained a sense of control over their lives. Regaining control meant that fear associated with genital herpes was no longer controlling them.

Regaining control was not considered as an arrival point where the participants had mastery over fear associated with genital herpes, but rather was viewed by the women as a process they must continue for the rest of their lives. There was an understanding that fear associated with genital herpes was influenced by physical, social and psychological events in their lives.

In this phase the unknowns of controlling information and controlling herpes became more certain over time even though individual responses could not be counted on 100% of the time. Each woman arrived at a better understanding of what fear management strategies worked best for her personally. As a result, the women had different expectations of controlling fear because they knew they were engaged in a lifetime process unless a cure for

genital herpes was found. Changing expectations increased the energy women had to devote to forgiving and moving on.

Forgiving. Contracting genital herpes permanently and profoundly changed the lives of the women in the study. The women saw forgiveness as a way to free themselves of the anger and betrayal they felt following the critical event of being diagnosed with genital herpes. Flannigan (1992) defined forgiveness as a mechanism of restoring peace, survival and as a basic need of conscience. Forgiveness involved naming the source and choosing to forgive.

Naming the source. Women in the study needed to know who gave them genital herpes. The women wanted to be able to confront, to blame the person responsible for giving them genital herpes.

I'm mad. I just want the chance to tell the person who gave it to me.

If I knew who gave me this I could face my accuser with my head held up high!

I told him [husband], I said the doctor said that I had herpes and then after that I didn't say a word. He knew I was mad and then that night he just came out and started talking to me and I said I need you to get checked out to make sure that you have or don't have it to see where I got it. Then he agreed to go get checked out and that's when we found out he had it.

The ability to confront or blame made an apology possible and/or gave the women a specific person to focus on forgiving.

I try to think of him a human being. We all have our faults. Thinking of him as a person somehow makes it easier to forgive.

I try to remember we are all human, we all make mistakes. Recognizing the person is human is the most important - sometimes the hardest part.

Flannigan (1992) supports the importance of knowing who to blame for an injury. According to Flannigan, without the opportunity to confront an offender directly, the injured person must repair the injury on their own. Otherwise, the person might waste her life waiting for an apology or a chance to face the offender.

Not knowing the source of the virus added another layer of stigma to having genital herpes. Women in the study feared not being able to answer questions regarding the source of the virus. They were afraid not knowing would result in being labeled promiscuous. Not knowing increased the fear of disclosure for most women.

I would feel worse if I didn't know. First of all, people will think you have a lot of partners, you know, that makes you feel even worse that you know your getting paid back for having so many partners. Knowing where I got it, especially with the rape factor, means I don't have to feel guilty. I don't have to worry that the next man I'm with thinks I'm

the kind of person that sleeps around either. I mean whenever anybody gets an STD, any STD in the world, people automatically think 'oh that person sleeps around'. Which isn't true, it just isn't true.

Not knowing makes me crazy. That's the first thing everybody asks "who gave it to you?"

Not being able to name the source also increased the fear of passing it on and raised concerns about exposure to other STDs. For one participant, not knowing meant she had to live with the fear of wondering if she had given genital herpes to someone else and if she had been exposed to other STDs. In response to this concern she reflected on previous partners and struggled to convince herself that her infection was recent and which limited the potential number of contacts. Knowing the source of genital herpes, or at least the time frame of the infection, allowed her to determine additional risks.

Not knowing where this came from, that's a big problem for me. Because I don't know, I've been with like six people my whole life. I've been with this guy for like a year and there was a guy previous to that just shy of three months. So you know, where did it come from? Who else could I have subjected them to me having it [herpes], what else have I been exposed to? But I stress out a lot so I think that I would already have had an outbreak if I got it a long time ago.

Choosing to forgive. Flannigan (1992) defined forgiveness as moving forward into the future. Women in this study saw forgiveness as a necessary step toward

moving on with their lives. It was a step they had to consciously choose to take. They could choose to let the fear resulting from contracting genital herpes govern their lives from the moment of diagnosis on or choose to forgive their partners and move on with their lives.

Intentionally was an important factor in deciding to forgive. Believing a partner intentionally gave someone herpes was harder to forgive. Several women in the study made "excuses" for their partners by attributing the transmission of genital herpes to drunkenness, drugs or lack of knowing.

Well I broke up with him and he came over to my house one night and he was drunk and drugged and he raped me. He doesn't remember.

He didn't know he had herpes. We found out about it together. It's hard to stay mad at him if he didn't know.

It's not like he gave it [herpes] to me on purpose. He didn't think I could get it if he didn't have a sore. He should have told me but it's done now.

Excusing the partner made it easier to forgive the injury by reframing the event from a betrayal to an unfortunate event where no one was really to blame. Both of the women in the study who had chosen to forgive their partners had facilitated forgiving through excusing.

One participant described forgiving as a survival strategy. She felt she wouldn't be able to continue living if she didn't or couldn't forgive her partner:

I don't know why I'm so forgiving. I guess I would kill him otherwise. Ordinarily, I mean if someone you knew willingly gave you something. I don't know, I mean I always figured if anybody would have given me something that I would go can blow up their car or something, you know. All of a sudden it happens to you and it's not like you can take medicine and it can go away. You are constantly reminded of it and you can't deny it happened and I have to [forgive] or else I wouldn't be able to live, you know?

The process of forgiving was extended by one participant to include forgiving a man who had sexually rejected her because she had herpes.

I understand [being rejected] because you know, if a man I liked or once liked would tell me that [he had herpes] I would run in the other direction. I mean I wouldn't want to deal with something like that. I forgave him quicker than I forgave the guy who gave it [herpes] to me.

Choosing not to forgive prevented women from moving on with their lives. One participant felt a strong sense of betrayal because she found out her husband was cheating on her when she was diagnosed she said:

I very much believe in forgiveness. Forgiveness is important to healing. I haven't forgiven my husband for bringing herpes home to me. I think that's why after three years I'm not really accepting herpes. I accept that I have herpes. I don't accept that herpes is a part of me.

Women in the study also spoke of forgiving themselves. One participant believed forgiving her partner was the only way to forgive herself.

I work at forgiving him. I'm not there yet but I'm trying. I know I played a part in it [getting herpes] too. I should have made him wear a condom. If I don't forgive him how will he ever forgive myself, ya know? It's going to take time, a long time.

Moving on. Women in the study described successful management of genital herpes as learning to manage fear. Fear of pain, disclosure, and passing it on made the women feel out of control of their lives. Fourteen (14) of the women in the study said they did not feel they were "doing well" with genital herpes. For them doing well meant putting genital herpes in the background of their lives and feeling free of fear to live their lives the way they wanted to. When asked to describe what would be different if they were doing well, participants replied they would like to feel less worry, be more comfortable and put herpes in the past:

I guess I wouldn't worry about it [herpes] as much. I would just get on with my life. Manage as best I could and not let it interfere with living a normal life. You know, go on and date, get married, have kids. Just make the best of it.

I think I do real bad with it [managing fear]. I would like to be more comfortable [physically and

emotionally] than I am right now. I would like my life back.

Just try to get over what's really wrong with me, trying to put it in the past, what's really wrong with me, I think about it but I'm trying not to too much worry about it.

Only two participants described themselves as "doing well". These participants described themselves as feeling free to live their lives with minor interruptions from genital herpes outbreaks. They had moved on with their lives.

I tell myself it's [herpes] already there and its not going to go away. You just move on with your life, ya know. Although, I wish they would find something to get rid of it.

I don't worry about it so much anymore. No ones knows but my boyfriend and he is OK with it. I don't let it interfere with my life.

Summary

The process of managing the fear trajectory depicts how low income women in the study responded to the problem of pervasive fear resulting from being diagnosed with genital herpes. The phases of managing the fear trajectory included: controlling information; controlling herpes; and regaining control of their lives. Women in the study controlled information about genital herpes through selective disclosure, distancing and selectively choosing information. The women used body listening, reading the

signs, recognizing triggers and tending to herpes as strategies to control herpes. Women who were able to forgive and move on expressed a feeling of having regained control over the fear in their lives.

CHAPTER 7
SUMMARY AND RECOMMENDATIONS FOR PRACTICE AND FUTURE RESEARCH

Every illness has a story and this study tells the story of low income women with genital herpes. The purpose of this grounded theory study was to generate a substantive theory about the response of low income women to the critical event of being diagnosed with genital herpes. Fear emerged as the basic social psychological problem faced by the women participating in this study. Following the critical event of being diagnosed with genital herpes, fear became a persistent part of their daily lives. Types of fear included fear of pain, fear of disclosure and fear of passing herpes on. For women in the study, fear was mediated by illness severity, pregnancy, relationship stability, and remembering herpes. Participants responded to fear through the process of managing fear. Managing Fear had three phases: controlling information; controlling herpes; and regaining control. Controlling information was a protective stance that allowed low income women to limit

who knew they had genital herpes; and to select the nature and amount of factual and personal information received. The women controlled herpes through body listening, reading the signs, recognizing triggers and tending to herpes. Regaining control freed the women in the study to get on with their lives through the processes of forgiving and moving on.

Recommendations for Practice

Access to Care

Low income women do not experience the same access to health care that other socioeconomic groups do. In addition to problems with limited access to health care providers, they also have decreased access to treatment and diagnostic advances. For example, low income women often do not have timely access to medications and full access to diagnostic tools such as culturing and/or serology's. These disadvantages limit the low income woman's ability to successfully manage fear.

The severity of the social ramifications of being diagnosed with genital herpes demands confirmatory cultures and the availability of counseling if needed. Additional barriers identified in the study included: long waiting room times, lack of transportation, and lack of

anticipation of child care needs. Researchers have identified responding to the needs of low income women resulted in improved clinic attendance (Kissinger et al., 1995). Improved clinic attendance may contribute to controlling the spread of genital herpes through educational programs and availability of anti-viral agents.

Awareness of Fear

The results of this study bring fear to light as a relevant problem faced by low income women with genital herpes. Awareness of fear as the basic social psychological problem has direct implications for clinical practice. The framing of fear as having a trajectory that can be individually shaped, even though the incurable course of genital herpes cannot be altered, opens the door for creative nursing interventions that are outside the current standard of care. Recognizing fear as a relevant problem for low income women following the critical event of being diagnosed with genital herpes suggests that direct nursing care/guidance would be particularly important during the initial diagnostic event. It also means recognizing that nursing care strategies for a patient who is learning to manage the fear trajectory may need to be focused on assessing progress in the areas of controlling

information, controlling herpes, and regaining control. In this context, medical management of genital herpes is seen as a collaborative process between the HCP and the patient. It is understood that the work of managing fear falls to the individual and those around them and places the HCP in an assistive role. This conceptualization of the client-as-partner is consistent with the shifting images of chronic illness as described by Thorne & Paterson (1998).

Importance of Trust

This study increases the awareness of the importance of trust in patient-nurse relationships. Trust creates an environment in which low income women feel free to disclose genital herpes without fear of being treated differently or judged harshly. Trust encourages nurses to listen to women experiencing genital herpes to gain an awareness of the genuine problems they face. Assessment questions must be broader than those limited to the medical story. Nurses must be willing to enter into relationship with low income women to hear their stories, to understand the meaning the disease has for them and to assist them in their struggle to live day-to day with genital herpes. By listening to the patient's story, nurses can come to know what their patients believe and understand about genital herpes.

Nursing strategies reflecting that understanding may result in increasing the number of low income women who are able to successfully manage their fear trajectories.

In the absence of trust, low income women may determine the risks of disclosure outweigh the benefits. Choosing not to disclose to HCPs limits the provider's ability to assist them and is particularly problematic during pregnancy and during evaluation and treatment for depression.

Recognizing Chronic Nature of the Disease

Genital herpes is a communicable disease that has no cure. The notion of chronicity in genital herpes implies long term management. The model of managing fear predicts that there will be ups and downs as low income women struggle to develop courses of action in response to changes in fear projections. Changing the health care focus from managing acute exacerbation of the virus to shaping the fear trajectory takes what Corbin (1993) calls fateful determinism out of the illness. This reframing allows the HCP to offer more positive messages and focus less attention on the incurable nature of the disease.

Recognizing Individual Variability

This study suggests it can not be assumed that fear associated with genital herpes automatically decreases over time. "Theoretically, we can look back on the evolution of anyone's trajectory, noting it's shape up to the present moment" (Corbin & Strauss, 1988, p.43). Recognizing fear trajectories are influenced by physical, social and psychological events in the lives of low income women requires nurses to periodically review fear trajectories. Evaluating individual past, current and projected trajectories may be a useful strategy for adjusting future fear management plans. For example, a woman may be managing well until a breakup of a long term relationship causes her to have to consider dating and the risk of new disclosures. She projects that the stress will increase the frequency and severity of her outbreaks. In this case, the woman may want to consider beginning suppressive therapy and attending a support group until she projects a decrease in her fear trajectory.

Patient Education

Currently, patient education content focuses on the medical facts of genital herpes and on strategies to reduce transmission. The study reveals a need to redesign

existing educational materials to include more practical information and individual variation such as body awareness, disclosure strategies, comfort measures, and stigma management.

Study Limitations

All participants in this study experienced illness symptoms severe enough to seek medical attention, experienced recognized recurrences, and were recruited through traditional health care providers including public health units, planned parenthood, hospitals and private nurse practitioners. Therefore, the sample was not representative of all low income women with genital herpes.

Sample Representation Problems

The sensitive nature of the topic presented several problems in gaining access to participants. For example, institutions generally did not allow advertising the study through posters due to concerns about offending other patients and/or negatively impacting the image of the institution. The study poster was designed to solicit interview volunteers and included information such as selection criteria and telephone contact numbers for the researcher. The poster was included in the materials presented for IRB approval at each institution. With the

exception of the public health units that allowed posters in all areas, other institutions generally limited advertising posters to specific treatment rooms or private conference areas. Some institutions would not allow any public advertising of the study. Limited access to study information and contact numbers of the researcher may have limited the number of participants in the study who chose not to disclose the fact they had genital herpes to their current provider. I received three calls from women responding to the poster. Two of the callers wanted information about genital herpes but did not want to participant in the study. Advertising constraints also meant that I had to rely on HCPs to remember the study was in progress, screen sexual histories for genital herpes, ask patients if they would like to participant and forward information to me. I attempted to mitigate these problems though frequent contact with the various providers and by camping out at one public health unit STD clinic every day for two months. My physical presence served as a reminder of the study and after a while the HCPs began to actively search for participants.

In order to gain access to participants through the public health units, IRB approval had to be gained at the state level. This was a lengthy process that was complicated by a lack of understanding and/or valuing of qualitative research and the sensitive nature of the topic. Interview questions surrounding sexual history and sexual practices of the participants were especially disconcerting for the committee. Also at issue was the informed consent process. The State IRB was the only institution that required a signed informed consent in place of the requested participant abstract. The requirement of signing their name may have intimidated some of the participants and influenced their decision to participate in the study. The signed consent was also problematic when participants preferred to protect their identify by choosing a telephone interview in place of a face to face interview. In this situation, the committee required a colleague to listen to the consent process and counter sign the consent form validating adequate protection of the participant's human rights. This requirement limited telephone interviews to times and places where a colleague was available. Knowing someone other than the researcher would hear their voice

and possibility know their name may have influenced their decision to participate.

Every researcher who studies a particular subject faces a sampling problem concerning the range and type of individuals to be sampled. This study looked at low income women as a group and therefore may mask important differences between ethnic groups. A basic assumption of Grounded Theory is that not everything has been discovered yet (Stern, 1985). Future studies exploring the experience of living with genital herpes might focus on specific groups of low income women such as blacks or Latinos to highlight salient differences between groups. Recommendations for future research include expanding the sample to more fully represent the diversity of the experience of living with genital herpes for low income women.

Research Recommendations

HIV+ Women with Genital Herpes

Only one of the participants in the study was known to be HIV+. She expressed fears that were similar to the other women in the study and described herpes as being more problematic for her than HIV. Herpes simplex virus is considered to be one of the opportunistic infections that

take advantage of weakened immune systems. For people with suppressed immune systems, herpes can become a potentially life threatening infection. Recurrences of genital herpes are lengthy and require higher doses of anti-viral therapy. HIV+ individuals are also at increased risk of developing resistant strains of HSV. Resistant strains of HSV occur in 1% of people with normal immune function and in up to 5% of people with compromised immune function (Ebel, 1998). Since the voice of only one HIV+ woman was reflected in this study, more qualitative studies are needed to identify issues of importance regarding how this group of women responds to living with genital herpes.

Pregnant Women with Genital Herpes

Pregnancy emerged in this study as a factor mediating fear. Four of the women participating in the study were pregnant at the time of the interview. This group differed from the other women in terms of the amount of fear expressed over placing their unborn children at risk of contracting genital herpes. A study focusing specifically on how pregnancy impacts the fear trajectories of low income women might reveal additional strategies pregnant women use in shaping their fear trajectory and the

conditions under which pregnant women choose to disclose or not disclose a history of genital herpes to their HCPs.

Pregnant women had information needs that were different from other women in the study. Research exploring the nature and depth of information required to manage fear without generating fear through "overtelling" would be useful in providing relevant care to this group of women.

Predicting Successful Management

Researchers have reported that less than one third of the people who contract genital herpes manage it successfully (Luby & Klinge, 1985). Only two of the participants in this study (12.5%) described themselves as managing the disease well. Successful management was defined by health care providers as: accepting you have herpes, disclosure to partners and HCPs, practicing safe sex, and seeking appropriate health care for outbreaks. In contrast, low income women in the study focused on managing the fear trajectory. Managing fear was indicative of successfully living with genital herpes because fear kept them from feeling in control of their lives. Further studies are needed to test whether the factors identified

in this study are predictive of successful management of genital herpes for low income women.

Non-Symptomatic Body Awareness

Non-symptomatic genital herpes is thought to contribute to the wide spread transmission of the disease. Research suggests 60% of seropositive persons who are unaware of HSV infection can be taught to successfully recognize recurrent symptoms (Ebel, 1998). Qualitative studies that describe body awareness experiences of women with genital herpes are needed to provide the knowledge base for culturally sensitive, meaningful educational programs.

Educational Programs

Currently, educational programs for low income women focus on the medical story of genital herpes and transmission control. Knowledge of this type was found to both increase and decrease levels of perceived fear. In a recent study by Lanier and Sloan (1996) the impact of educational content on fear associated with AIDS was explored. As a result of their findings, the authors recommended decreasing emphasis on biological functions and increasing emphasis on coping strategies, communication skills and self protection behaviors. Further study is

needed to determine under what conditions specific types of information increase or decrease fear levels in low income women with genital herpes.

APPENDIX A
ADVERTISEMENT

Volunteers are needed to participate in a research study of women with genital herpes. Participants 18 years of age and older will be asked to describe in an audiotaped interview what it has been like for them to have genital herpes.

Information learned from the study may help nurses better understand the experience of living with genital herpes and lead to improved nursing care for women.

If you are interested in participating in this study, please contact:

Shirley Gordon, RN
College of Nursing
Florida Atlantic University



or

Speak with your health care provider

APPENDIX B
PARTICIPANT ABSTRACT

I am a registered nurse (RN) and a doctoral student at the University of Florida, College of Nursing. I am looking for volunteers to take part in a research study to explore what it is like for women to live with genital herpes.

I would like to talk with you for about an hour in a private place that is comfortable for you.

I would like to record your interview with me on an audiotape so I can be sure to get your story correct. The tape of your interview will be erased after it has been transcribed. Numbers will be used in place of your name on the tape and on the typed copy. Your name will not be shared with anyone. However, copies of your typewritten interview may be shared with my research advisor and study group.

Your participation in this study is completely voluntary and you are free to stop the interview or leave the study at any time without effecting your healthcare.

You will not be paid to take part in this study.

You may benefit from sharing your experience and the information you provide may be helpful to other women with genital herpes.

There are no expected risks to you. Some people find talking about genital herpes helpful while others may become upset. If you become upset and wish to talk with someone, you will be referred to your regular health care provider for assistance.

If you have any questions about this study or your participation in the study, you may contact:

Shirley Gordon, RN
College of Nursing
Florida Atlantic University
[REDACTED]

APPENDIX C
INFORMED CONSENT HRS DISTRICT IX

I am a registered nurse (RN) and a doctoral student at the University of Florida, College of Nursing. I am looking for volunteers to take part in a research study to explore what it is like for women to live with genital herpes.

I would like to talk with you for about an hour in a private place that is comfortable for you.

I would like to record your interview with me on an audiotape so I can be sure to get your story correct. The tape of your interview will be erased after it has been transcribed. Numbers will be used in place of your name on the tape and on the typed copy. Your name will not be shared with anyone. However, copies of your typewritten interview may be shared with my research advisor and study group.

Your participation in this study is completely voluntary and you are free to stop the interview or leave the study at any time without effecting your healthcare.

You will not be paid to take part in this study.

You may benefit from sharing your experience and the information you provide may be helpful to other women with genital herpes.

There are no expected risks to you. Some people find talking about genital herpes helpful while others may become upset. If you become upset and wish to talk with someone, you will be referred to your regular health care provider for assistance.

APPENDIX D
INTERVIEW GUIDE

1. Tell me about discovering you had genital herpes.
 - a. How did you discover you had it?
 - b. What was your medical treatment like?
2. How does it effect your daily life?
3. How does it effect your relationships with people?
 - a. your sexual relationships?
 - b. relationships with other women?
 - c. relationships with people at work?
 - d. relationships with family?
4. How do you see yourself since discovering you have herpes?
5. How have you changed?
6. What do you see as the worst thing about having herpes?
7. Describe anything positive about having herpes.
8. How would you describe the meaning your experience has had for you?
9. How do you see your future?
10. What would you tell others, men and women about herpes?
11. What is important for healthcare providers (like nurses) to know about herpes?
12. How did you feel about participating in this study?

13. Would you be willing to respond to more questions at another time?
13. Do you know any other women with herpes that might like to participate in this study?

APPENDIX E
DEMOGRAPHIC DATA

Interview # _____ Date _____
_____ Location _____

Recruitment Source _____

Ethnic Background:

Black _____	White _____
Hispanic _____	Native American _____
Other _____	Asian _____

Education level _____

Occupation: Employed _____

Unemployed _____

Marital Status:

Single _____
Married _____
Partnered _____
Widowed _____
Separated _____
Divorced _____

Number of sexual partners in the past year: _____

Condom use: always _____
frequently _____
occasionally _____
never _____

Diagnosis with genital herpes 19__

Outbreak triggers:

menstruation _____	stress _____
sleeplessness _____	fever _____
illness _____	heat _____
intercourse _____	unknown _____
other _____	

Medication:

none __
 Acyclovir
 Topical __
 Systemic __
 Acute __
 Suppressive __
 other _____

Number of outbreaks per year _____

Illicit Drug Use:

HX:		Past Year
__	Marijuana	__
__	Cocaine	__
__	Amphetamines	__
__	Hallucinogens	__
__	Benzodiazepines	__
__	Inhalants	__

Self Help Strategies:

REFERENCES

- Alonzo, A. & Reynolds, N.R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. Social Science Medicine, 41(3), 303-315.
- Aral, S. (1994). Sexual behavior in sexually transmitted disease research: An overview. Sexually Transmitted Diseases, 21(2 suppl.), S59-S64.
- As we age. (1997, Fall). The Helper, XIX(3), 1, 5-6.
- Banfield, (1970). The unheavenly city. (2nd ed.). Boston: Little Brown.
- Becker, T., Stone, K. & Cates, W. (1986). Epidemiology of genital herpes infections in the United States: The current situation. Journal of Reproductive Medicine. 31(suppl. 5), 359-364.
- Belle, D. (1990). Poverty and women's health. American Psychologist, 45(3), 385-389.
- Beirman, S. (1983). A retrospective study of 375 patients with genital herpes infections seen between 1973 and 1980. CUTIS, 31, 348-565.
- Blumenfield, M., Smith, P.J., Milazzo, J., Seropian, S. & Wormser, G.P. (1987). Survey of attitudes of nurses working with AIDS patients. General Hospital Psychiatry, 9, 58-63.
- Bok, S. (1979). Lying: Moral choice in public and private life. New York: Vintage Books.
- Bowers, B. J., (1988). Grounded Theory. In B. Sarter (Ed.). Paths to Knowledge (pp. 33-59). New York, NY: NLN Publications.

Brandt, A.M. (1988). The syphilis epidemic and it's relation to AIDS. Science, 239, 375-380.

Breault, A.J. & Polifroni, E.C. (1992). Caring for people with AIDS: Nurses' attitudes and feelings. Journal of Advanced Nursing, 17, 21-27.

Brink, P. J. (1991). Issues of reliability and validity. In J.M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue (2nd ed.) (pp.164-186). Newbury Park, CA: SAGE Publications.

Brown, G., Bhrolchain, M., & Harris, T. (1975). Social class and psychiatric disturbance among women in an urban population. Sociology, 9, 225-254.

Brown, Z.A., Benedetti, J., Ashley, R., Burchett, S., Selke, S., Berry, S., Vontver, L.A., & Corey, L. (1991). Neonatal herpes simplex virus infections in relation to asymptomatic maternal infection at the time of labor. New England Journal of Medicine, 324, 1247-1252.

Brown, Z.A., Vontuer, & L.A., Benedetti, J. (1987). Effects non infants of a first epidose of genital herpes during pregnancy. New England Journal of Medicine, 317(20), 1246-1251.

Carrieri, V.K. & Janson-Bjerklie, S. (1986). Strategies patients use to manage the sensation of dyspnea. Western Journal of Nursing Research, 8, 284-305.

Charmaz, K. (1991). Good days bad days. New Brunswick, N.J.: Rutgers University Press.

Chenitz, W.C. & Swanson, J.M. (1986). From practice to grounded theory, Menlo Park, CA: Addison Wesley.

Chenitz, W.C. & Swanson, J.M. (1989). Counseling clients with genital herpes. Journal of Psychological Nursing, 27(9), 11-17.

Children's Defence Fund. (1979). American children and their families. Washington, DC: Author.

Chuang, T. (1988). Neonatal herpes: Incidence prevention, and consequences. American Journal of Preventative Medicine, 4, 47-53.

Cimprich, B.A., (1992). A theoretical perspective on attention and patient education. Advances in Nursing Science, 14, 39-51.

Cochrane, S. & Mays, V. (1989). Women and AIDS-related concerns: Roles for psychologists in helping the worried well. American Psychologist, 44(3), 529-535.

Collins, P.H. (1989). The social construction of black feminist thought. Signs: Journal of Women and Culture in Society, 14, 745-773.

Cook, J.A. & Fonow, M.M. (1986). Knowledge and women's interests: Issues of epistemology and methodology in feminist sociological research. Sociological Inquiry, 56(1), 2-29.

Cooper, M.C., (1990). Chronic illness and nursing's ethical challenge. Holistic Nursing Practice, 5(1), 10-16.

Corbin, J. (1993). Response to "Operationalizing the Corbin & Strauss trajectory model for elderly clients with chronic illness". Scholarly Inquiry for Nursing Practice: An International Journal, 7(4), 265-268.

Corbin, J. & Strauss, A. (1988). Unending work and care. San Francisco: Jossey-Bass.

Corbin, J. & Strauss, A. (1991). A nursing model for chronic illness management based upon the trajectory framework. Scholarly Inquiry for Nursing Practice: An International Journal, 5(3), 155-174.

Corey, L. (1990). Genital herpes. In K.K. Holmes, P. Mardh, P.F. Sparling, P.J. Wiesner, W. Cates, S.M. Lemon, & W.E. Stamms (Eds.) Sexually Transmitted Diseases (391-413). New York: MacGraw Hill.

Corey, L. (1993). Herpes simplex virus infections during the decade since the licensure of acyclovir. Journal of Medical Virology, Supplement 1, 7-12.

Corey, L. Adams, H. Brown, Z., & Holmes, K. (1983). Genital herpes simplex infections: Clinical manifestations, course, and complications. Annals of Internal Medicine, 98, 958-972.

Denzin, N.K. (1978). Sociological methods. NY: McGraw Hill.

Drob, S. (1986). Psychosocial implications of genital herpes. Medical Aspects of Human Sexuality, 20, 97, 100, 102, 104.

Duffy, M.E. & Hedin, B.A. (1988). New directions for nursing research. In N.F. Woods & M. Catanzaro (Eds). Nursing Research: Theory and Practice (pp. 530-539). St. Louis: C.V. Mosby.

Ebel, C. (1998). Managing herpes: How to live and love with a chronic STD. (Rev. Ed). Research Triangle Park: American Social Health Association.

Edwards, R. (1993). An education in interviewing: Placing the researcher and the research. In R. Lee and C. Renzetti (Eds.), Researching sensitive topics, Newbury Park, NJ: Sage.

Elion, G.B. (1993). Acyclovir: Discovery, mechanism of action, and selectivity. Journal of Medical Virology, 1(2), 2-6.

Fernald, J. (Ed.). (1947). Funk & Wagnalls standard handbook of synonyms antonyms & prepositions (Rev. ed.). New York: Funk & Wagnalls.

Flanigan, B. (1992). Forgiving the unforgivable: Overcoming the bitter legacy of intimate wounds. New York: Macmillan.

Flannery, M.C. (1983). Teaching and the media. American Biology Teacher, 45(5), 282-285.

Fleming, D., McQuillan, G., Johnson, R., Nahmias, A., Aral, S. Lee, F. & St.Louis, M. (1997). Herpes simplex virus type 2 in the United States, 1976 to 1994. The New England Journal of Medicine, 337(16), 1105-1111.

Fox, M.S., Cassmeyer, V., Eaks, G.A., Hamera, E., O'Connell, K., & Knapp, T. (1984). Blood glucose self-monitoring usage and its influence on patients' perceptions of diabetes. Diabetes Education, 10, 27-31.

Fox, R. (1957). Training for uncertainty. In R. Merton, G. Reader, & P. Kendal (Eds.) The Student Physician. Cambridge: Harvard University Press.

French, M. (1992). The war against women. New York: Summit Books.

Fridson, E. (1965). Disability as social deviance. In M. Sussman (Ed.) Sociology and Rehabilitation. Washington, DC: American Sociological Association.

Fuchs, V. (1967). Redefining poverty and redistribution Income. The public interest, 8.

Fullilove, M.T., Fullilove, R.E., Haynes, K. & Gross, S. (1990). Black women and AIDS prevention: A view towards understanding the gender rules. The Journal of Sex Research, 27(1), 47-64.

Glaser, B.G. & Strauss, A. (1967). Discovery of grounded theory. Chicago: Aldine.

Glaser, B.G. (1978). Theoretical sensitivity. Mill Valley, CA.: The Sociology Press.

Goffman, E. (1963). Stigma: notes on the management of a spoiled identity. Englewood Cliffs, N.J.: Prentice-Hall.

Goldberg, L.H., Kaufman, R.H., Kurtz, T.O., Conant, M.A., Eron, L.J., Batenhorst, R.L., & Boone, G.S. (1993). Continuous five year treatment of patients with frequently recurring genital herpes simplex virus infection with acyclovir. Journal of Medical Virology Supplement, 1, 45-50.

Gonder-Frederick, L.A., Cox, D.J., Pennebaker, J.W., & Babbit, S.A.. (1986). Blood glucose symptoms beliefs of diabetic patients: accuracy and implications. Health Psychology, 37, 363-367.

Gordon, S. & Sherrod, K. (1996). Readability of generic and commercial patient educational materials for genital herpes. Unpublished manuscript.

Greenberg, D. (1992, July). Adventures in safe sex. Playboy, pp.74-77, 144-145.

Griffin, C. (1987). Young women and the transition from School to unemployment: A cultural analysis. In G.Weiner & M. Arnot (Eds.), Gender under scrutiny: New Inquiries in Education. London: Hutchinson.

Guidelines for women's health care. (1996). Washington D.C.: The American College of Obstetricians and Gynecologists.

Habif, T.P. (1995). The diagnostic manual of herpesvirus infections. Research Triangle Park, N.C.: Burroughs Wellcome Co.

Hall, J. (1994). The experience of lesbians in Alcoholics Anonymous. Western Journal of Nursing Research, 16(5), 556-576.

Hall, J. & Stevens, P. (1991). Rigor in feminist Research. Advances in Nursing Science, 13(3), 16-29.

Hall, L.A., Williams, C.A., & Greenberg, R.S. (1985). Supports, stressors and depressive symptoms in low income mothers of young children. American Journal of Public Health, 75, 518-522.

Hamera, E. Cassmeyer, V. O'Connell, K.A., Weldon, G.T., Knapp, T.M., & Kyner, J.L. (1988). Self-regulation in individuals with type II diabetes. Nursing Research, 37, 363-367.

Harger, J., Pazin, G. & Breinig, M. (1986). Current understandings of the natural history of genital herpes simplex infections. Journal of Reproductive Medicine, 31(suppl. 5), 365-373.

Helping the medical community to help you. (1996, Winter). The Helper, XVIII(4), 1,5-7.

Herpes the new sexual leprosy. (1980). Time, p.38.

Herpes the scourge of the sexual revolution. (1983, January). Readers Digest, p.p. 128-132.

Hilliard, J, Kitchel, C., Turner, U.G., Keeling, R.P., & Shank, R. (1984). Knowledge and attitudes of university health service clients about genital herpes: Implications for patient education and counseling. Journal of American College Health, 33, 113-117

Hobsbawn, E.J. (1968). Poverty. In D. Sills (Ed.). International encyclopedia of the social sciences. Vol 12. NY: McMillan Company and Free Press.

Hutchinson, S. (1993). Grounded theory: The method. In P.L. Munhall & C.J. Boyd (Eds.), Nursing Research: A Qualitative Perspective (pp. 180-212). NY: NLN Publications

Inhorn, M. C. (1986). Genital herpes: an ethonographic inquiry into being discreditable in American society. Medical Anthropology, 17(4), 59-62.

Isenberg, M. (1919). The need for more and better tuberculosis nurses. The American Journal of Nursing, 20(1), 121-123.

Jagger, A.M. (1988). Feminist Politics and Human Nature. Sussex, England: Rowman & Little.

Jennings, B. Callahan, D. & Callan, A.L. (1988). Ethical challenges of chronic illness. Hastings Center Report, 18(1), 1-16.

Johnson, R.E., Nahmias, A.J., Magder, L.S. Lee, F.K., Brooks, C.A., & Snowden, C.B. (1990). An epidemiologic survey of the prevalence of herpes simplex virus type 2 infection in the United States. New England Journal of Medicine, 321, 7-12.

Kachigan, S.K., (1986). Statistical analysis. New York: Radius Press.

Kaplan, G., Roberts, R., Camacho, T. & Coyne, J. (1987). Psychological predictors of depression: Prospective evidence from the human population laboratory studies. American Journal of Epidemiology, 125, 206-220.

Katz, J. (1984). Why doctors don't disclose uncertainty. The Hastings Center Report, 14(2), 35-44.

Kaufman, S.R. (1988). Toward a phenomenology of boundaries in medicine: chronic illness experience in the case of stroke. Medical Anthropology Quarterly, 2(4), 338-354.

Keller, M.L., Jadack, R.A. & Mims, L.F. (1991). Perceived stressors and coping responses in persons with recurrent genital herpes. Research in Nursing and Health, 14, 421-430.

Kissinger, P., Clark, R., Rice, J. Kutzen, H., Morse, A., & Brandon, W. (1995). Evaluation of a program to remove barriers to public health care for women with HIV infection. Southern Medical Journal, 88(11). 1121-1125.

Koutsky, L.A., Ashley, R.L., Stevens, C.E., Wolner-Hanssen, P. Critchlow, C.W., Kiviat, N. & Corey, L. (1990). The frequency of unrecognized type 2 herpes simplex lesions among women: Implications for the control of genital herpes. Sexually Transmitted Diseases, 1,9-94.

Koutsky, L.A., Stevens, C.E., Holmes, K.K., Ashley, R.L., Kiviat, N.B., Critchlow, C.W., & Corey, L. (1992). Underdiagnosis of genital herpes by current clinical and viral-isolation procedures. New England Journal of Medicine, 326, 1533-1539.

Kulhanjian, J.A., Soroush, V., & Au, D.S. (1992). Identification of women at unsuspected risk of primary infection with herpes simplex type 2 during pregnancy. New England Journal of Medicine, 326(14), 916-920.

Lanier, M. & Sloan, J. (1996). Cynicism, fear, communication and knowledge of acquired immunodeficiency syndrome (AIDS) among juvenile delinquents. Crime & Delinquency, 42(2), 231-243.

Lau, R., Williams, S., Williams, L. & Brook, R. (1992). Psychological problems in chronically ill children. Journal of Community Health, 7(4), 250-261.

Leininger, M.M. (1985). Life health-care history: Purposes, methods and techniques. In M.M. Leininger (Ed.), Qualitative research methods in nursing (pp. 119-132). Orlando: Grune and Stratton.

Lee, R. & Renzetti, C. (1993). The Problems of researching sensitive topics: An over view and introduction. In R. Lee & C. Renzetti (Eds.). Researching sensitive topics, Newbury Park, NJ: Sage.

Lewis, O. (1966). La Vida: A Puerto Rican family in the culture of poverty. NY: Random House.

Light, D.J. (1979). Uncertainty and control in professional training. Journal of Health and Social Behavior, 29(30), 320.

Lincoln, Y.S. & Guba, E.G. (1985). Naturalistic inquiry. Newbury Park, NJ: Sage.

Luby, E. & Klinge, V. (1985). Genital Herpes: A pervasive psychological disorder. Archives of Dermatology, 121, 494-497.

Makosky, V. (1982). Sources of stress: events or conditions? In P. Belle (Ed.). Lives in stress: Women and depression (pp. 35-53). Beverly Hills, CA: Sage.

Mayo, L. (1956). Problem and challenge. Guide to action on chronic illness. NY: National Health Council. pp. 9-13,35,55.

Mays, S. & Cochrane, V. (1988). Issues in the perception of AIDS risk and risk reduction activities by Black and Hispanic/Latina women. American Psychologist, 43(11), 949-957.

Mead, G.H. (1934). Mind, self, and society. Chicago: University of Chicago Press.

Meaningful care. (1998). American Journal of Nursing, 98(6), 58.

Meleis, A.I. (1990). Being and becoming healthy: The core of nursing knowledge. Nursing Science Quarterly, 3(3), 107-114.

Merry, S. (1981). Urban danger. Philadelphia: Temple University Press.

Mertz, G.L., Jones, C.C. & Mills, J. (1988). Long term acyclovir suppression of frequently recurring genital herpes virus infection: A multi-center double-blind trial. Journal of the American Medical Association, 260, 201-6.

Mishel, M.H. (1988). Uncertainty in illness. Image: Journal of Nursing Scholarship, 4, 225-232.

Mishel, M.H. (1990). Reconceptualization of the uncertainty in illness theory. Image: Journal of Nursing Scholarship, 22(4), 256-262.

Morris, W. (Ed.). (1982). The American heritage dictionary (New college ed.). (1981). Boston: Houghton Mifflin Company

Nahmias, A., Lee, F.K., & Beckman-Nahmias, S. (1990). Seroepidemiological and sociological patterns of herpes simplex virus infection in the world. Scandinavian Journal of Infectious Diseases, 569, 19-23.

Nahmias, A. & Norrild, B. (1979). Herpes simplex virus 1 and 2: basic and clinical aspects. Disease A Month, 14, 49.

The New Scarlet Letter. (1982). Time, p. 62-68.

Niimura, M., & Emmet, S. (1989), Herpes proenitalis. In L.C. Parish & F. Gschnait (Eds.) Sexually transmitted diseases: A guide for clinicians (pp. 166-181). New York: Springer-Verlag.

O'Connell, K. Hamera, E., Knapp, T. Cassmeyer, V. Eaks, G.A. & Fox, M.A. (1984). Symptom use and self-regulation in type II diabetes. Advances in Nursing Science, 6, 19-28.

Pacard, N.J., Haberman, M.R., Woods, N.F. & Yates, B.C. (1991). Demands of illness among chronically ill women. Western Journal of Nursing Research, 13(4), 434-457.

Parson, T. (1951). The Social System. Glencoe: Free Press.

Pearlin, L & Johnson, T. (1977). Marital status, life strains and depression. American Sociological Review, 42, 704-715.

Pendleton, D. (1983). Doctor-patient communication: A review. In D. Pendleton & J. Haltzer (Eds.), Doctor-patient communication (pp. 5-53). London, UK: Academic Press.

Pennebaker, J.W., Cox, D.J., Gonder-Frederick, L. Wunsch, M.G., Evans, W.S., & Pohl, S. (1981). Physical symptoms related to blood glucose in insulin diabetics. Psychometric Medicine, 43, 489-500.

Pliskin, K. (1995). Vagina dentata revisited. Culture, Medicine and Psychiatry, 19(4), 479-501.

Plummer, K. (1983). Documents of life: An introduction to the problems and literature of a humanistic method. London: Allen & Unwin.

Preventing transmission. (1997, Winter). The Helper, XX(4), 1, 4-7.

Price, M.J. (1993). Exploration of body listening: Health and physical awareness in chronic illness. Advances in Nursing Science, 15(4), 37-52.

Prober, C.C., Corey, L., & Brown, Z.A. (1992). The management of pregnancies complicated by genital infections with herpes simplex virus. Clinical Infectious Diseases, 15, 1031-8.

Rae, S. (1985). What happened to herpes? The New Statesman. 110, 33-34.

Ramos, M.C. (1989). Some ethical implications of qualitative research. Research in Nursing and Health, 12, 57-63.

Redfern, N. & Hutchinson, S. (1994). Women's experience of repeatedly contracting sexually transmitted diseases. Health Care for Women International. 15, 423-433.

Redfern, N. & Hutchinson, S. (1995). The process of developing personally sovereignty in women who repeatedly acquire sexually transmitted diseases.

Robinson, L., Bevil, C., Atcangelo, V., Reifsnnyder, J., Rothman, N., & Smeltzer, S. (1993). Operationalizing the Corbin & Strauss trajectory model for elderly clients with chronic illness. Scholarly Inquiry for Nursing Practice: An International Journal, 7(4), 253-264.

Seiber, J. (1980). Being ethical: professional and personal decisions in program evaluation. In R. Perloff & E. Perloff (Eds.). Values, ethics and standards in evaluation (pp. 33-59). NY:NLN Publications.

Seiber, J. (1993). The ethics and politics of sensitive research. In R. Lee and C. Renzetti (Eds.). Researching sensitive topics. Newbury Park, NJ: Sage.

Schmid, G. (1990). Approach to the patient with genital ulcer disease. Medical Clinics of North America, 74, 1559-1572.

Schmid, G.P., Daline, J.R., & Weiss, N.S. (1987). Sexually transmitted diseases and tubal infertility. Sexually Transmitted Diseases, 14, 12-16.

Schorfheide, A.M., Eaks, G.A., Hamera, E.K., & Cassmeyer, V. (1989). Enhancing self-care in diabetes management using self-regulatory processes. Journal of Community Health Nursing, 6, 165-171.

Skoldenberg, B. Jeansson, S. & Wolontis, S. (1975). Herpes simplex virus type 2 and acute aseptic meningitis. Scandinavian Journal of Infectious Diseases, 7, 227-232.

Slovic, P., Fischhoff & Lichtenstein, S. (1982). Fact versus fears: Understanding perceived risk. In D. Kahneman; P. Slovic & A. Tversky (Eds.), Judgement Under Uncertainty: Heuristics & Biases. (pp 463-489). Cambridge: Cambridge University Press.

Smeltzer, S.C. (1991). Use of the trajectory model in multiple sclerosis. Scholarly Inquiry for Nursing Practice: An International Journal, 2(1), 219-234.

Sontag, S. (1978). Illness as Metaphor. New York: Farrar, Straus and Giroux.

Stamm, W.E., Handsfield, H.H., Rompalo, A. M., Ashley, R. L., Roberts, P.L. & Corey, L. (1988). The association between genital herpes ulcer disease and acquisition of HIV infection in homosexual men. Journal of the American Medical Association, 260, 1429-1433.

Stanley, L. & Wise, S. (1983). Breaking Out: Feminist Consciousness and Feminist Research. Boston: Routledge and Kegan Paul.

Steele, E., Mitchell, J., Greywolf, E., Belle, D., Change, W., & Schuller, R.B, (1982). The human cost of discrimination. In D.. Belle (Ed.). Lives in Stress: Women and depression (pp. 109-119). Beverly Hills, CA: Sage.

Stern, P.N., Allen, L. & Moxley, P. (1982). The nurse as grounded theorist: History, process and uses. The Review Journal of Philosophy and Social Science, 7(1,2), 200-215.

Stern, P.N., (1985). Using grounded theory method in nursing research. In M.M. Leininger (Ed.), Qualitative research methods in nursing (pp. 149-160). Orlando: Grune and Stratton.

Stevens, P.E. & Hall J.M., (1988). Stigma, health beliefs and experiences with health care in lesbian women. Image, 20(2), 69-73.

Stewart, A.E. (1918). Public health nursing and tuberculosis. The American Journal of Nursing, 19(5), 374-378.

Strauss, A. & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques, Newbury Park, CA: SAGE Publications.

Strauss, A. Corbin, J., Fagerhaugh, S. Glaser, B., Maines, D. Suczek, B. & Wiener, C. (1984). Chronic illness and the quality of life, 2nd Ed., Mosby: St. Louis.

Stryker, S. (1980). Qualitative analysis. NY:NY Cambridge University Press.

Swanson, J.M. & Chenitz, W.C., (1990). Psychosocial aspects of genital herpes: A review of the literature. Public Health Nursing, 7(2), 96-104.

Swanson, J.M. & Chenitz, W.C., (1993). Regaining a valued self: The process of adaptation to living with genital herpes. Qualitative Health Research, 3(3), 270-297.

Swanson, J.M., Remy, L., Chenitz, C. Chastain, R. & Trocki, K. (1993). Illicit drug use among young adults with genital herpes. Public Health Nursing, 10(3), 197-203.

The Terrible curse of Herpes. (1982, March 4). Rolling Stone, p. 23-24.

Thomas, S. (1994a) From the culture of poverty to the culture of single motherhood: The new poverty paradigm. Women and Politics, 14(2).

Thomas, S. (1994b). Gender and poverty. NY: Garland Publishing.

Thorne, S. & Paterson, B. (1998). Shifting images of chronic illness. Image: Journal of Nursing Scholarship, 30(2), 173-178.

Thorne, S. & Robinson, C. (1989). Guarded alliance: Health care relationships in chronic illness. Image, 21(3), 153-157.

Townsend, P. (1979). Poverty in the United Kingdom: A survey of household resources and standards of living. London: Allen Lane Books.

Tyring, S. & Sadovsky, R. (1996). Management of herpesvirus infections. Monograph of the American Family Physician, 2.

US Bureau of the Census. (1990). Estimates of poverty Including the value of non-cash benefits. Technical Paper #51. Washington DC: Government Printing Office.

Wald, A, Zeh, J., Davis, L.G., & Corey, L. (1996). Suppression of subclinical shedding of herpes simplex virus type 2 with acyclovir. Annals of Internal Medicine, 124, 8-15.

Warmbrodt, L (1993, May). Herpes, the shock, the stigma, the ways you can ease the emotional pain. RN, 47-49.

Whitley, R., Arvin, A. & Prober, C. (1991). Predictors fo morbidity and mortality in neonates with herpes simplex virus infections. New England Journal of Medicine, 324(7), 450-454.

Wing, R.R., Epstein, L.H., Nowalk, M.P., & Lamparski, D.M. (1986). Behavioral self-regulation in the treatment of patients with diabetes mellitus. Psychological Bulletin, 99, 78-79.

Worth, D. (1989, November/December). Sexual decision making and AIDS: Why condom promotion among vulnerable women is likely to fail. Studies in Family Planning, 20(6), 297-307.

Zambrana, R., Dunkel-Schetter, & Scrimshaw, S. (1991). Factors which influence use of prenatal care in low-income racial-ethnic women in Los Angeles County. Journal of Community Health, 16(5), 283-295.

Zopf, M. (1992). American Women in Poverty. Westport, Conn: Greenwood Press.

BIOGRAPHICAL SKETCH

Shirley Countryman Gordon received her Bachelor of Science in Nursing from the University of Florida in 1976. She began her professional experience in emergency room nursing at Community Hospital in West Palm Beach, Florida. She has also worked in adult health, telemetry and geriatric nursing.

Shirley pursued graduate education at the University of Texas at Austin where she earned a Master of Science in Nursing in 1981. She focused her clinical practice on the care of chronically ill adults, infection control, and staff education. She began teaching at the university level in 1986. She is currently an Assistant Professor of Nursing at Florida Atlantic University. She is a nationally certified bereavement facilitator and serves as a founding member of the Board of Directors for a pregnancy and infant loss support organization.

Research interests in the areas of stigma and chronicity led Shirley to develop and direct the Head Lice

Treatment and Prevention Project: A Focus of the Community Pased Nursing Model at Florida Atlantic University, College of Nursing. The project is funded through the Palm Beach County Health Care District. She has spoken numerous times on the subject of chronic head lice at local, state and regional conferences.

Shirley is a member of the Sigma Theta Tau National Honor Society. She has received several awards for Leadership and Excellence in Academic Advising from Florida Atlantic University.

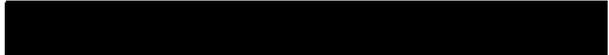
I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.


Sally A. Hutchinson, Chair
Professor of Nursing

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.


Kathaleen C. Bloom
Assistant Professor of Nursing

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.


Karolyn L. Godbey
Associate Professor of Nursing

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.


M. Josephine Snider
Associate Professor of Nursing

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.


John C. Sutherland
Professor of Journalism
and Communications

This dissertation was submitted to the Graduate Faculty of the College of Nursing and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

December 1998



Dean, College of Nursing



Dean, Graduate School