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HYPEREMESIS GRAVIDARUM AND PATIENT SATISFACTION:  
PATIENTS' PERCEPTIONS OF THE PATIENT-  
PHYSICIAN RELATIONSHIP

presented by

Shari L. Munch

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**HYPEREMESIS GRAVIDARUM AND PATIENT SATISFACTION:  
PATIENTS' PERCEPTIONS OF THE PATIENT-  
PHYSICIAN RELATIONSHIP**

**By**

**Shari L. Munch**

**A DISSERTATION**

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## **ABSTRACT**

### **HYPEREMESIS GRAVIDARUM AND PATIENT SATISFACTION: PATIENTS' PERCEPTIONS OF THE PATIENT- PHYSICIAN RELATIONSHIP**

**By**

**Shari L. Munch**

In the field of medicine, the patient-physician relationship is affected by complex societal attitudes and assumptions about women. Female patients, especially those with reproductive disorders, tend to be taken less seriously than their male counterparts, and their somatic complaints are more likely to be labeled by physicians as psychosomatic. One such diagnosis is hyperemesis gravidarum (HG), severe nausea and vomiting of pregnancy. Despite limited evidence that psychological factors cause HG, the presumption of a mostly psychogenic etiology has dominated medical literature for decades and may, therefore, contribute to a less than optimal patient-physician relationship as determined by patient satisfaction, an outcome measure of health care quality.

Particular aspects of women's lived experiences with HG that helped to shape their perceptions of the patient-doctor relationship were analyzed as a first step to giving voice to this patient population. This study investigated patients' own beliefs and their perceptions of their doctors' beliefs about the causal explanation of HG, the seriousness of the illness, and the impact of the illness upon patients' daily lives. Also examined

were the extent to which patients' beliefs were congruent with their perceptions of their doctors' beliefs, and patients' ratings of the humanistic characteristics of physicians that they deemed important.

The study employed both quantitative and qualitative research methodologies and was based on a retrospective, ex post facto research design. Ninety-six respondents who had experienced at least one inpatient hospitalization from January 1993 through April 1997 responded to interview questions that focused on their HG illness experience, including both inpatient and outpatient medical care.

Correlational analyses showed that Physician Humanism was the only independent variable found to be significantly associated with the dependent variable, Patient Satisfaction. However, the qualitative data suggested support for each of the research hypotheses such that respondents reported greater satisfaction when they perceived their doctors believed in a mostly biomedical etiology, believed the illness to be serious enough to warrant medical monitoring and intervention, understood the extent to which HG impacted a patient's life, shared patients' beliefs about each of these variables, and exhibited humanistic characteristics. Additional relevant data were presented, implications for practice and policy were addressed, and further research was suggested on women's health care, HG, and patient satisfaction.

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To the women who so willingly and enthusiastically participated in this project--women who endured much suffering and sacrifice in their striving to bring healthy babies into this world, and whose strength is to be admired.

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Dr. Howard Brody exemplified the essence of interdisciplinary study; they were always available to me, broadening my knowledge and zeal for philosophy, medical ethics, and teaching.

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I have often wondered why family and friends are mentioned last in an acknowledgment. In my case, it means that they have been the nearest and dearest people on this journey--those people for whom there are no words available in the written language to capture the way they have calmed the waters of my life. I will

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## CHAPTER I

### INTRODUCTION

#### Introduction and Problem Statement

In the field of medicine, the patient-physician relationship is the heart of the clinical encounter (Epstein, Campbell, Cohen-Cole, McWhinney, & Smilkstein, 1993). People consult doctors for a variety of reasons. In general, they perceive an actual or potential threat to the quality of their lives or fear that illness may shorten their lives (Little, 1995). The patient-physician relationship is the arena in which individuals hope to tell their story and assume that doctors will provide an accurate diagnosis, prognosis, and a plan for resolving or managing their distress.

Although medical knowledge and sophisticated technology are used to arrive at a diagnosis and treatment plan, it is interpersonal communication and interaction between patients and doctors that are the primary mechanisms for exchanging information (Ong, deHaes, Hoos, & Lammes, 1995; Peabody, 1927). Even in the absence of cure, imparting explanations for the illness in a manner that communicates compassion and respect for the dignity, worth, and belief system of the individual is not only essential as a matter of professional ethics (Barcia, 1993; Gordon, 1983; Nadelson, 1993), but may enhance healing (Brody, 1987) and positively influence patients' health outcomes (Kaplan, Greenfield, & Ware, 1989). Moreover, patients who perceive

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positive interpersonal interactions and humanistic characteristics in their doctors tend to report greater satisfaction with their medical care (Brody et al., 1989; DiMatteo, Taranta, Friedman, & Prince, 1980; DiMatteo, Hays, & Prince, 1986; Hauck, Zyzanski, Alemagno, & Medalie, 1990; Kenny, 1995; Ware, Snyder, Wright, & Davies, 1983).

The patient-physician relationship is one of the most complex among interpersonal relationships in that it involves "interaction between individuals of non-equal positions, is often non-voluntary, concerns issues of vital importance, is therefore emotionally laden, and requires close cooperation" (Ong et al., 1995, p. 903). In addition, cultural biases and gender stereotypes that influence us all impact this already complex relationship.

Societal attitudes and assumptions about women, and socialization of medical students to believe that women patients are less competent, present psychosomatic complaints, and are hysterical, can negatively shape the ways doctors interact with their female patients (Todd, 1989). A tendency for physicians to sometimes mislabel women's physical complaints as psychosomatic both in the presence of organic etiologic factors and when the underlying pathophysiological mechanism of the condition is unknown has been widely reported (Abell & Riely, 1992; Chesler, 1972; Corea, 1977; Foster, 1989; Hamilton, 1993; Krieger & Fee, 1994; Krieger, Rowley, & Herman, 1993; Lennane & Lennane, 1973; Nadelson & Notman, 1978; Stellman, 1990; Todd, 1989; Wallen, Waitzkin, & Stoeckle, 1979).

For example, there is some evidence that primary care physicians tend to overestimate the prevalence of psychological disturbance among female compared to



male patients (Redman, Webb, Hennrikus, Gordon, & Sanson-Fisher, 1991). In another study, it was found that physicians tended to judge female patients to be more emotional; however, they did not perceive female patients as less authentic or ill than male patients (Colameco, Becker, & Simpson, 1983). Similarly, Wallen et al. (1979) found that doctors were more likely to see their female patients' illness as psychologically caused and were more pessimistic about their recovery. The authors concluded that "physician stereotypes about female health and illness may have affected the interactions between female patients and their physicians" (p. 145).

Women with reproductive disorders, in particular, experience the impact of gender stereotypes and attitudes, especially when medical professionals are unable to uncover the specific etiology of the condition (Nadelson & Notman, 1990; Stellman, 1990). Clinical observation and a review of the literature suggest that hyperemesis gravidarum (HG) is an example of such a problem (Lennane & Lennane, 1973; Munch, 1991).

HG--severe nausea and vomiting during pregnancy--is a "diagnostic and therapeutic enigma for the obstetrician" (Starks, 1984, p. 253). HG remains a puzzling and debilitating condition for both doctors and patients because there is no known cause or cure. Prior to the use of intravenous (IV) fluids, HG was a significant factor leading to neurologic disturbance and even maternal death (Cowan, 1996; Williams, 1923). With advancements in IV fluid therapy, the risk of these outcomes is greatly reduced. Today, health care professionals often view the condition as more of a

nuisance. Some contend that patients with HG "garner little attention and engender little sympathy from their physicians" (Abell & Riely, 1992, p. 835).

Both biological and psychological theories of etiology for HG are areas of considerable controversy. The historical discourse in the medical literature that presumes a partly or wholly psychogenic etiology is pervasive (Atlee, 1934; Chertok, 1972; El-Mallakh, Liebowitz, & Hale, 1990; Fairweather, 1978; Harvey & Sherfey, 1954; Iancu, Kotler, Spivak, Radwan, & Weizman, 1994; Katon, Ries, Bokan, & Kleinman, 1980-81; Menninger, 1939; Uddenberg, Nilsson, & Almgren, 1971; Walton, 1973; Zechin & Hammer, 1982). Others contend that the etiologic claim of psychosomatic disorder is without any supporting scientific evidence (Callahan, Burnette, DeLawyer, & Brasted, 1986; Lennane & Lennane, 1973; Majerus, Guze, DeLong, & Robins, 1960; Neri, Levavi, & Ovadia, 1995; Peckham, 1929). While it seems illogical to suggest that HG is never impacted by or a result of psychological factors, physicians who presume a psychogenic etiology in HG may discount or minimize the severity of symptoms and the full impact of the illness on the pregnant woman's quality of life (O'Brien & Naber, 1992). This, in turn, may potentially contribute to a less than optimal patient-physician relationship, as well as poor maternal and infant outcomes.

### Purpose of the Research

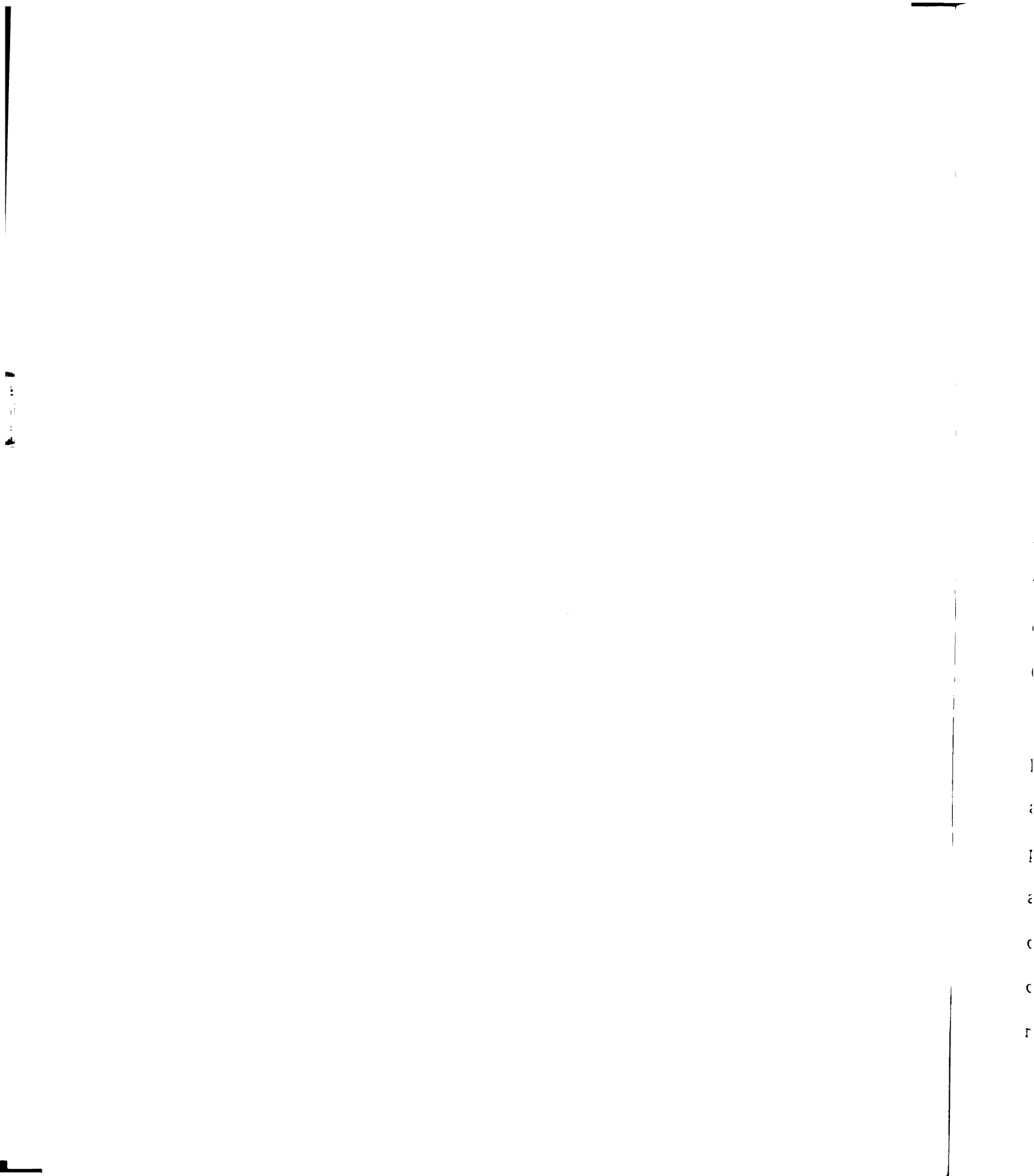
The aim of this research study is to better understand patients' perceptions of the patient-physician relationship that affect patients' satisfaction with the overall medical care received from their doctors in the treatment of HG. In so doing, it investigates patients' own beliefs and their perceptions of their doctors' beliefs about the cause of

HG, the seriousness of the illness, and the impact of the illness upon patients' daily lives. It also examines the extent to which patients' beliefs are congruent with their perceptions of their doctors' beliefs. Finally, it explores the humanistic characteristics of physicians deemed important by HG patients.

### Rationale for the Study

In general, there is a need for empirical research addressing the psychosocial care of specific medical complications of pregnancy. Although there are similar stressors and responses common to patients experiencing pregnancy complications, research regarding the unique impact of specific diagnoses upon life-style change, perception of risk, and anxiety is warranted (Monahan & DeJoseph, 1991). Also, the psychosocial differences between women with high-risk pregnancies caused by sudden (e.g., hyperemesis) versus chronic (e.g., preexisting diabetes) factors require further research (Schroeder-Zwelling & Hock, 1986).

More specifically, descriptive articles and research designs examining psychological predictors have typically presumed that HG is a psychosomatic disorder (Iancu et al., 1994; Novey & Goodhand, 1938; Tsoi, Chin, & Chang, 1988). It is not surprising, however, to find that the data support a relationship between psychosocial indicators and HG. Most women diagnosed with pregnancy complications experience considerable stressors common to and resulting from the pregnancy complication itself (Aboudi & Zager, 1995; White & Ritchie, 1984). Merely looking for psychological predictors tends to frame the question as an intrapsychic problem--a matter of the patient's supposed dysfunctional personality or poor coping. Rather, studies about



high-risk pregnancy, and this HG study in particular, that begin with the systematic examination of patients' experience with the illness (O'Brien & Naber, 1992) and the patient-doctor relationship may prove beneficial.

Additionally, HG is an expensive obstetric problem frequently characterized by multiple admissions to the high-risk antenatal unit (Godsey & Newman, 1991) and the utilization of medical treatments such as total parenteral nutrition (Charlin, Borghesi, Hasbun, VonMulenbrock, & Moreno, 1992). Moreover, there is evidence to suggest that women who suffer from severe HG during early pregnancy are more likely to give birth to low birth weight infants (Chin & Lao, 1988), which has implications for costly neonatal and pediatric treatment. Thus, despite technological advancements that have virtually eliminated death from HG, the condition warrants serious attention because of its potentially severe effects both to mother and baby in those in whom it does occur (Callahan et al., 1986).

Certainly all health care professionals play an important role in the care of patients. It is the patient-doctor relationship, however, that is of particular importance and the focus of this study. Obstetricians, in particular, often serve in the role of primary care physician for the pregnant woman. In the primary care setting, "patients and physicians develop relationships that have historical precedents and the expectation of continuity" (Epstein et al., 1993, p. 386). The physician follows the patient during outpatient office appointments, throughout inpatient hospitalization, and may follow multiple generations of a family.

The significance of this relationship is even greater in the life of a pregnant woman. The personal quality of the relationship is characterized not only by the intimate nature of the medical examinations, but by the frequent office visits that occur throughout, at least, a 10-month period of time. The relationship takes on a unique importance because of a mutual concern for the unborn baby.

Women experiencing pregnancy complications may be especially vulnerable, both physically and emotionally (Kemp & Hatmaker, 1989; MacMullen, Dulski, & Pappalardo, 1992; Merkatz, 1978), and may, thereby, place a greater emphasis on the importance of the relationship with their doctors. Similarly, physicians' emotional reactions to women experiencing pregnancy complications can become intensified as a result of the inherent stress of an uncertain outcome, the complex emotional responses of the high-risk pregnant patient, and the presence of two patients in obstetric care--the woman and the fetus (Wohlreich, 1986).

To further our understanding about the impact of doctors' attitudes and behaviors on HG patients' health behaviors, physical and psychological states, and overall patient satisfaction, it is important to first understand women's perceptions of their doctors' attitudes as manifested in the context of the patient-doctor relationship. By filling a void in the literature regarding HG, the findings of this study will provide preliminary data regarding quality of care issues. Data resulting from this study may eventually serve as a catalyst for subsequent studies that examine the implications of the quality of care for HG patients on measures such as patient satisfaction, cost containment, maternal outcomes, and infant outcomes. Current gaps in the empirical

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literature include quality of care issues (e.g., relationship between professional psychosocial interventions and maternal, birth, and infant outcomes); cost containment issues (relationship between professional psychosocial interventions and length of hospital stay/multiple admissions); patients' satisfaction with the care received from their physicians; and innovative psychosocial interventions that will meet the complex needs of this at-risk population in a cost-effective manner.

Understanding factors that influence patient satisfaction can help social workers contribute to patients' health and quality of life, as well as impact organizations and other health care providers (Hsieh & Kagle, 1991). As members of interdisciplinary teams, social workers have a responsibility to work collaboratively with colleagues from other health care disciplines to address the psychosocial needs of both the women experiencing HG and their families. Finally, Oakley (1993a) expressed well the value of the contribution of social scientists to medicine. She asserted:

A comprehensive evaluation of medical care or of obstetric care must include both the technical efficiency and effectiveness of medicine on the one hand, and its social relations on the other. . . . We need to know, for instance, not only whether particular therapies work, but also how important the social relations of doctor and patient are in making them work or in explaining why they do not work. (p. 33)

### Research Questions

The overarching question for this study was: What patient perception factors are most highly associated with patients' satisfaction with the medical care received from their physicians in the treatment of HG? The specific questions guiding the research fell into three categories. The first category pertained to questions about



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perceptions of doctors' beliefs about the HG experience. The second category pertained to the question of shared beliefs. The third category pertained to questions about perceptions of physician humanism. Following are the specific research questions that were addressed:

1. What is the relationship between patients' perceptions of their doctors' beliefs about the causal explanations of HG and their satisfaction with the medical care received from their doctors?
2. What is the relationship between patients' perceptions of their doctors' beliefs about the degree of seriousness of the HG and their satisfaction with the medical care received from their doctors?
3. What is the relationship between patients' perceptions of their doctors' beliefs about the impact of the HG on the patients' lives and their satisfaction with the medical care received from their doctors?
4. What is the relationship between the total congruence score of patients' own beliefs and their perceptions of their doctors' beliefs about the causal explanation, the degree of seriousness, and the extent of impact on the patients' lives, and their satisfaction with the medical care received from their doctors?
5. What is the relationship between patients' perceptions of their doctors' humanism and their satisfaction with the medical care received from their doctors?

### Research Hypotheses

Hypothesis 1: Patients who perceive that their doctors believed in a mostly biomedical causal explanation for HG will report greater satisfaction with the medical care received from their doctors. (Higher scores on measures of

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biomedical causal explanations will be positively associated with higher scores on reported patient satisfaction with care.)

**Hypothesis 2:** Patients who perceive that their doctors believed that the HG was a serious medical condition will report greater satisfaction with the medical care received from their doctors. (Higher scores on measures of the degree of seriousness will be positively associated with higher scores on reported patient satisfaction with care.)

**Hypothesis 3:** Patients who perceive that their doctors believed that the HG significantly impacted the patients' lives will report greater satisfaction with the medical care received from their doctors. (Higher scores on the measure of extent of impact on a patient's life will be positively associated with higher scores on reported patient satisfaction with care.)

**Hypothesis 4:** Patients who perceive that they and their doctors shared the same perceptions about the causal explanation, the degree of seriousness, and the extent of impact of HG on the patients' lives, as measured by the total congruence score, will report greater satisfaction with the medical care received from their doctors. (The lower the total congruence score, the greater the reported patient satisfaction with care.)

**Hypothesis 5:** Patients who perceive their doctors as more humanistic will report greater satisfaction with the medical care received from their doctors. (Higher scores on physician humanism will be positively associated with higher scores on reported patient satisfaction with care.)

### Overview

Chapter I contained the introduction and problem statement, the purpose of the research, and the rationale for the study. The research questions and hypotheses also were set forth. Chapter II provides a review of the relevant literature pertaining to this study. The research methodology is described in Chapter III, and the findings are presented in Chapter IV. Chapter V contains a summary of the study, major findings, conclusions drawn from the findings, implications, and recommendations.

## CHAPTER II

### REVIEW OF THE LITERATURE

Several bodies of research served to inform the research questions of this dissertation study. The four broad topics presented in this review of literature are women's health care and gender bias, hyperemesis gravidarum, the patient-doctor relationship, and patient satisfaction.

#### Women's Health Care and Gender Bias

An enormous body of scholarly work exists on the topic of gender and health. The scholarly work represents many disciplines, such as sociology, social work, psychology, feminist studies, philosophy, nursing, psychiatry, and, to a lesser extent, general medicine and obstetrics and gynecology. Although not the focus of this dissertation, limited attention has been given to historical attitudes and events that have shaped women's health care. Acknowledging this broad literature base provides a historical context and serves as the backdrop from which this study's research questions, in part, are framed. Following is an overview of the literature on gender and women's health pertinent to this study. It incorporates the topics of gender-biased diagnosing, historical attitudes about women and health, sex-role socialization and medical education, social construction of illness, and patient-doctor communication.

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### Gender-Biased Diagnosing

The occurrence of physicians who dismiss women's physical complaints as nonserious and label those complaints as psychosomatic because of stereotypic beliefs about women and the female body has been identified as a problem by the lay (Boston Women's Health Book Collective, 1984), scholarly (Ehrenreich & English, 1973; Oakley, 1993a; Scully, 1994), and clinical (Armitage, Schneiderman & Bass, 1979; Council on Ethical and Judicial Affairs, 1991; Hamilton, 1993; Krieger et al., 1993; Malterud, 1993; Nadelson & Notman, 1990) communities for more than 30 years.

The article that seems to have captured the most attention from the scholarly community and is the most frequently cited in the literature on gender-biased diagnosing of female medical conditions appeared in the February 1973 issue of the New England Journal of Medicine. Psychiatrist K. Jean Lennane and her physician husband, R. John Lennane, of the Renal Unit at Prince Henry Hospital in Australia, raised their concerns about possible "sexual prejudice" in four disorders including dysmenorrhea, nausea of pregnancy, and labor pain. For instance, 30 years after the biological relationship between dysmenorrhea and ovulation was demonstrated in 1940, without evidence of a failure to adapt to the feminine role, standard gynecologic textbooks still emphasized a psychogenic cause (Lennane & Lennane, 1973). The authors claimed that the ready acceptance of a psychological origin of these conditions had occurred without scientific evidence. Lennane and Lennane concluded:

Illogical, persistent and damaging beliefs constitute prejudice, and in view of the fact that all these conditions affect women, whereas the majority of specialists and textbook authors are men, it is tempting to postulate an underlying sexual basis for this prejudice. (p. 291)

To date, two empirical studies have specifically addressed the topic of gender-biased diagnosing of female medical conditions. Armitage et al. (1979) investigated physicians' responses to five common complaints in a sample of 104 men and women. In each of the five complaints they found that men received more extensive work-ups than did women. Although speculative, the authors concluded that the male physicians in their study tended to take illness more seriously in men than in women and that "they [physicians] might be responding to current stereotypes that regard the male as typically stoic and the female as typically hypochondriacal" (p. 2187).

Conversely, one article was found that challenged the now-pervasive assumption that there are gender disparities in health care that are biased against women. Verbrugge and Steiner (1981) replicated the Armitage et al. (1979) study utilizing national data and a considerably larger sample size. They found few significant sex differences in the extent and content of diagnostic services given for the five common complaints. The authors concluded that this topic poses an important hypothesis for research and public discourse; however, they advised caution in assuming physician sex-bias in light of little empirical evidence.

Still, the shift in the literature, from the early belief that many complaints by women are psychogenic to the awareness that this belief is the result of gender bias, appears to have been influenced by three primary factors. Initially, feminist scholars began to challenge traditional psychoanalytic theories that postulated, for instance, that women's biology determined a natural female role and that many reproductive-related



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complaints were a rejection of femininity (Chodorow, 1989; Nadelson & Notman, 1990).

Second, feminist political attention to women's health issues gained momentum in the mid- to late 1980s. Attention shifted from women as providers of health care (e.g., women entering medical school) to their experiences as recipients of health care (Lewin & Olesen, 1985). An example is that policy makers and researchers neglected to include women in clinical trials. Biomedical research findings have been based on male subjects and generalized to women, leaving physicians with inaccurate and possibly harmful information as to how to apply medical advances to their female patients. Exclusion from landmark studies that impacted public health practice prompted outrage by many women of the scientific and lay communities. The 1988 government-financed study that found that men who took an aspirin every other day had a 44% lower heart attack rate than the male control group (Silberner & Friedman, 1990) ignored how women might be affected by this aspirin treatment, despite the fact that coronary artery disease is the leading cause of death for women as well as for men (Ayanian & Epstein, 1991). The longstanding bias in biomedical research (Silberner & Friedman, 1990) led to the National Institutes of Health (NIH) establishing the Office of Research on Women's Health in 1990 (Pinn, 1994).

Third, advances in medical technology have created a prime opportunity to study sexism in medicine. Medicalization is the process of defining physical states or behaviors as an appropriate focus of medical attention (Wright & Morgan, 1990). Some have contended that the medicalization of many female conditions such as childbirth

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(Rothman, 1991) and premenstrual symptoms (Morell, 1988) labels women's natural biological responses as "disease." As such, medical technology is often relied upon rather than listening to the patient's description of symptoms. Physician Charles King (1992) stated, "Somehow facts produced by technological feats are seen as more accurate than are subjective signs and symptoms" (p. 3). For example, unless the fetal monitor documents contractions, pregnant women are frequently told that their complaints of labor are unfounded (Rothman, 1991). Thus, despite the lack of specific empirical evidence documenting that physicians diagnose female and male patients differently based on sexual stereotypes, there is remarkable agreement in the literature that the problem of gender-biased diagnosing of female medical conditions exists.

### Historical Attitudes About Women and Health

The literature cites a substantial number of medical diagnoses that have been and continue to be negatively impacted by gender bias. These medical conditions include those pertaining exclusively to women, as well as those experienced by both women and men. However, it is the female reproductive system that has been the primary focus giving rise to a variety of erroneous and stereotypical beliefs about women's "nature" and their predestined social role in society. The psychosexual and sociocultural significance of the uterus can be traced to ancient times. The term hysteria is derived from the Greek word, *hystera*, and negative connotations were associated with the term because the uterus was believed to be central to diseases of women (Bachmann, 1990). Hysteria means "wandering uterus" (Nadelson & Notman, 1990) and is based on Greek medical lore of the connection between the mind and the body in women. Bachmann

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(1990) stated, "The condition of hysteria was attributed to the wandering of the uterus to different parts of a woman's body, causing a variety of symptoms and erratic behavior" (p. 41). Bachmann concluded that although the notion of a wandering uterus has been discarded, many still consider the emotional outbursts and sensory disturbances associated with hysteria to be more common in women.

Similarly, with the development of psychological theories, various reproductive disorders and related phenomena were labeled psychogenic and were considered to be related to conflicts about femininity or childbearing. Sigmund Freud, for example, described somatization with his metaphor "the mysterious leap from the mind to the body" (Nadelson & Notman, 1990, p. 1), and theoretical concepts of early psychoanalytic and psychodynamic theory attempted to explain certain reproductive-related phenomena in terms of psychoactive forces. Examples of female medical conditions often presumed psychogenic include, but are not limited to, premenstrual symptoms (McIlhany, 1985; Rossignol & Phillips, 1992), dysmenorrhea (Corea, 1977; Lennane & Lennane, 1973), painful childbirth (Lennane & Lennane, 1973), infertility (Nadelson & Notman, 1990), and pelvic pain with unknown etiology (Stellman, 1990).

In addition to female medical conditions, historical beliefs and underlying attitudes about women have also affected the diagnosing of medical disorders shared by women and men. One example is interstitial cystitis (painful bladder disease). Women presenting with symptoms are frequently labeled with the psychiatric diagnosis of somatization disorder, which results in subsequent mistreatment of the disease (Webster, 1993). In the classic 1978 urology text, Campbell's Urology, Harrison et al.

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(cited in Webster, 1993) stated, "Interstitial cystitis . . . may represent the end state of a bladder that has been made irritable by emotional disturbance. . . . A pathway for the discharge of unconscious hatreds" (p. 236).

A second example is coronary artery disease--the leading cause of death in women (Steingart et al., 1991). Empirical studies have found that physicians pursue a less aggressive management approach to coronary disease in women (Steingart et al., 1991); hospitalized women receive fewer diagnostic and therapeutic procedures than men (Ayanian & Epstein, 1991). Other examples are the gender disparities regarding women's access to kidney transplantation and the diagnosis of lung cancer (Council on Ethical and Judicial Affairs, 1991).

In sum, the prevailing attitudes about women and health prior to feminist theory were influenced by at least three factors. First, the early Greeks believed that women's emotional "nature" was caused by their womb. Second, psychoanalytic theorists posited that women's physical complaints were often symbolic rejections of the "feminine role." Ehrenreich and English (1973) described yet a third factor that contributed to physicians' and society's beliefs about women. This phenomenon, "female invalidism," was prevalent during the mid-nineteenth century.

Female invalidism was pervasive among the upper- and upper-middle-class female culture. Women were told by their doctors that they were naturally sickly and weak; there was the societal belief that women were more ladylike if they were pale and faint in appearance. In addition, retiring early to bed due to "sick headaches" and "nerves" was viewed as fashionable (Ehrenreich & English, 1973). By 1910, this



condition began to fade but was replaced with the new disease of "hysteria." Although most modern women do not have (or do not desire) the luxury of idleness, today's woman is expected to work in and outside of the home even when she is sick. Women's health is now viewed as a moral state (Oakley, 1993b). That is, a good woman is a healthy woman; she continues to do all of the household tasks and other work expected of her, whether she is ill or not. Although sickness is not viewed as "feminine" today, the myth of female frailty, albeit emotional, continues to seep into medical thinking in instances when doctors assume a psychogenic etiology for women's physical symptoms when a physical cause is undetectable.

#### Sex-Role Socialization and Medical Education

Phillips (1995) argued that "gender stereotypes have permeated much of medical pedagogy and practice" (p. 510). The author noted the importance of sex-role stereotypes in physicians' assessments, hypothesis generation, diagnoses, treatments, and conceptualizations of health and illness. Researchers who have emphasized sex-role socialization often have addressed communication patterns among women and men and the androcentric bias in medical education. Corea (1977) explained the phenomenon of male physicians perceiving female patients as hysterical by stating that women are conditioned to more freely acknowledge and express their emotions, whereas "men are trained in the stoicism of the masculine stereotype" (p. 78). Todd (1989) noted that researchers have found that women seek medical care more than men, which maintains the assumption that women are the more sickly, weaker sex. The author questioned whether the frequency of women's medical visits is better explained by the fact that sex-

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role socialization leads to women's greater willingness to admit a problem and seek help.

Writers also have addressed stereotypes arising from beliefs about women's "nature" and their impact on sex-role socialization. These stereotypes have been perpetuated in medical textbooks and medical education to which many practicing physicians today have been exposed. In their classic study, Scully and Bart (1978) analyzed 27 general gynecology texts published in the United States from 1943 to 1972 and found an emphasis on traditional female sex-role stereotypes. For example, women were described as "anatomically destined to reproduce, nurture, and keep their husbands happy" (p. 283). In the 1971 textbook Office Gynecology, Greenhill (cited in Corea, 1977) observed that "many women, wittingly or unwittingly, exaggerate the severity of their complaints to gratify neurotic desires" (p. 75). In the 1971 text Obstetrics and Gynecology, Wilson (cited in Scully & Bart, 1978) stated, "The traits that compose the core of female personality are feminine narcissism, masochism and passivity" (p. 288).

With regard to medical education, lecturers have been observed to refer to patients exclusively as "he" except when discussing a hypothetical patient with a psychogenic disease; then they automatically shift to using "she." Female medical students reported that lecturers frequently referred to women as "hysterical mothers," "hypochondriacs," and "old ladies," and 72% of physicians referred spontaneously to a woman when asked to describe the "typical complaining patient" (Corea, 1977). More recent research has detailed how language and metaphors are used today in both

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medical texts and clinical practice to describe women's reproductive-related functions in terms of weakness and pathology (Martin, 1992).

### Social Construction of Illness

The social construction of illness refers to the idea that determinants of health, illness, and disease are constructed by individuals and groups of individuals within their particular culture at various points in history (Good, 1994; Kleinman, 1980). Thus, what is considered disease in one culture may not be in another, and within the same culture disease categories often change. For example, until recent challenges to theories of human sexual development, combined with political and social action, the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association defined homosexuality as a mental illness.

One agent of a culture's "social construction of sickness" is the medical profession. It is the medical profession that defines illness in theory, identifies illness in practice, and oversees those identified as "sick" (Ehrenreich & Ehrenreich, 1974). That is, it determines which biological phenomena admit one to the sick role and which are regarded as minor, psychosomatic, or otherwise ineligible for medical treatment. For example, Scully (1994) noted that in the 1800s many physicians found vaginal examinations distasteful and believed that women were merely seeking sexual gratification in their requests for the examination. Today, women who do not obtain regular pap smears will most likely be viewed by physicians as irresponsible with regard to their health maintenance. Thus, what counted as health and illness was, and continues to be, defined in the absence of women patients.

Furthermore, the institution of medicine as a social structure not only defines illness, but is an agent of social control. Ehrenreich and English (1973), in reference to the historical period of the late 1800s and early 1900s, asserted, "The doctor's view of women as innately sick did not, of course, *make* them sick, or delicate, or idle. But it did provide a powerful rationale against allowing women to act in any other way" (p. 22). For example, medical arguments were used as justifications for not allowing women into politics or medical school.

### Patient-Doctor Communication

Unlike their male counterparts, female patients are exposed not only to expert power, but to gender power as well (Malterud, 1993). Todd (1989) explored the various ways that power is manifested in conversations between doctors and patients. And, using a stratified random sample of 336 tape-recorded interactions between physicians and their female and male patients, Wallen, Waitzkin, and Stoeckle (1979) found that doctors were more likely to see female patients' illnesses as psychologically caused. In addition, the authors reported that although women received more explanation time from their doctors than did men, the explanations received were not as extensive and were less likely to match the level of technicality of the women's questions. The authors suggested that, in the "micro-politics" of the information process, "withholding of medical information from women must be considered in connection with the question of power" (p. 145). Furthermore, there is some recent evidence to suggest that when women of color and women who are economically poor ask questions, they are viewed by physicians as more "difficult" (Todd, 1989).

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Both verbal and nonverbal communication have been found to be related to patient satisfaction with medical care (DiMatteo et al., 1986). Patients have been found to be quite sensitive to the nonverbal communicative behaviors of their physicians, looking for cues from their doctors as ways to gauge the appropriateness of their emotional responses (Ong et al., 1995). Because patients use a doctor's cues as an emotional barometer of sorts, they tend to be alert to any inconsistencies between doctors' verbal and nonverbal communication.

Still, in her extensive ethnographic study of doctor-patient communication, West (1984) found that although male doctors interrupted their patients (both female and male) more than patients interrupted their doctors, "both doctors and patients are implicated in this social construction of reality" (p. 155). West explained that both patients and doctors bring to the doctor-patient relationship beliefs about the presumed social roles of how doctors and patients should act during the encounters. The author concluded that the nature of the medical interview is not merely the result of doctors' "dominance" or patients' "passivity." Rather, both doctors' and patients' perceptions about information exchange and relational communication play an important role in the medical interview (Cegala, McNeilis, & McGee, 1995).

### Hyperemesis Gravidarum

Moving beyond the contextual "backdrop" of the gender and women's health literature, it is useful to turn now to the diagnosis of concern in this dissertation--HG. In so doing, attention is given to its definition and epidemiology, theories of etiology



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and treatment approaches, and the historical underpinnings contributing to a belief of psychogenesis.

### Definition and Epidemiology

One of the classic diagnostic symptoms of pregnancy is "morning sickness" (Williams, 1923), which is also commonly termed nausea and vomiting in pregnancy or NVP (Deuchar, 1995). Historically, nausea was believed to be the result of resentment and ambivalence of women ill-prepared for motherhood (Corea, 1977; O'Brien & Newton, 1991). Today, mild to moderate NVP is considered normal and common (O'Brien & Naber, 1992), encompasses mild symptoms of nausea and vomiting during the first trimester of pregnancy (occurrence throughout the pregnancy is the exception), and generally disappears by the twelfth to sixteenth week with nutritional status and weight not seriously affected. The reported incidence in American women ranges from 50% to 80% (Katon et al., 1980-81) to 50% to 90% (Abell & Riely, 1992) of all pregnancies.

In contrast, HG or "pernicious vomiting of pregnancy" (Williams, 1923) occurs when uncomplicated nausea and vomiting of pregnancy become intractable (Starks, 1984). The condition is characterized by symptoms of such severity as to require hospitalization and/or extensive outpatient treatment and includes, but is not limited to, symptoms of dehydration, electrolyte imbalance, weight loss often greater than 5% of body weight, and ptyalism (Abell & Riely, 1992). Like NVP, HG is a disorder of the first trimester of pregnancy; its onset occurs between the fourth and tenth weeks and typically resolves by the twentieth week, with rare cases persisting well into the second

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trimester (Abell & Riely, 1992). The typical illness course includes a gradual recovery, frequent relapses, multiple episodes of inpatient management, and/or the use of home health care services, such as intravenous hydration (Cowan, 1996; Naef et al., 1995).

The incidence of HG ranges from estimates of 1 to 3 cases per 1,000 (Charlin et al., 1992) to 1 to 10 per 1,000 pregnancies (Katon et al., 1980-81) in the United States and European societies. Cross-culturally, the incidence reported for Chinese women is within the range reported for European countries (Chin, Lao, & Kong, 1987). Nationally, epidemiological studies have shown that the overall rate of HG has decreased since 1983, yet the severity appears to have increased (Erick, 1995). In 1956, the American Council on Pharmacy and Chemistry developed the definition of HG and its symptoms (Fairweather, 1968). The diagnosis for hospitalized HG patients is classified by the numeric code of 643 in the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM; Practice Management Information Corporation, 1997).

### Theories of Etiology and Treatment Approaches

Biological theories. Both biological and psychological theories of etiology are areas of considerable controversy. Some of the proposed biochemical or hormonal theories include elevated human chorionic gonadotropin levels and vitamin B6 deficiency (Eller & Randall, 1945; Starks, 1984), thyroid toxicosis (Kimura et al., 1993), excess of estrogen secreted in pregnancy (Lennane & Lennane, 1973), allergic reaction to the corpus luteum of pregnancy (Rosen, 1955), and hyperolfaction (Erick, 1995). Medical treatment encompasses either one or a combination of the following

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interventions: restricted diet (Anderson, 1994), intravenous fluid therapy (Zimmerman & Strauss, 1989), nasogastric tube (Gulley, VanderPleog, & Gulley, 1993), and total parenteral nutrition (Boyce, 1992; Rayburn, Wolk, Mercer, & Roberts, 1986). Antiemetic medications such as compazine, vitamin B6, and phenergan have been used with variable success. Researchers recently have investigated the use of oral corticosteroids (Nelson-Piercy & DeSwiet, 1994), herbal remedies such as ginger root (Fischer-Rasmussen, Kjaer, Dahl, & Asping, 1990), acupressure (Belluomini, Litt, Lee, & Katz, 1994), and electrical stimulation of the vestibular system based on the theory that HG resembles the symptoms found in motion sickness (Golaszewski, Frigo, Schaller, & Mark, 1994).

Psychological theories. In a paper read before the Berlin Obstetrical Society in 1890, Kaltenbach, a German physician, was the first to suggest that vomiting of pregnancy is usually a manifestation of neurosis (Fairweather, 1978). However, it was the landmark study by physician Denys Fairweather of London, England--the most frequently cited in the NVP and HG literature--that embedded the presumption of psychogenic factors of moderate to severe NVP into the scholarly literature (O'Brien & Newton, 1991). The major proponent of the theory of psychogenesis is psychoanalytic theory. Traditional psychoanalytic theory purports that a pregnant woman's vomiting may represent various intrapsychic conflicts. The pregnant woman's vomiting has been associated with neurotic tendencies (Atlee, 1934), hysteria (Guze, DeLong, Majerus, & Robins, 1959), and as a symbolic rejection--an unconscious, oral attempt at abortion (Chertok, 1972). An ambivalent attitude (versus a marked rejection), representing

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conflict between wanting and rejecting the baby, also has been implicated (Chertok, 1972). Menninger (1939) thought that NVP was a rejection of femininity. Harvey and Sherfey (1954) implicated sexual frigidity and psychological immaturity in the etiology of HG. Others reported cases in which HG is sometimes manifested as a conversion disorder (El-Mallakh et al., 1990) and is generally believed to be associated with psychopathology (Iancu et al., 1994).

Social psychological theories shifted the paradigm from viewing vomiting of pregnancy as a psychiatric illness to that of a response to psychosocial stressors such as poverty and marital conflict (Tsoi et al., 1988; Tylden, 1968). Acknowledging the role of psychosocial stressors avoids the view that HG results from the inadequate personality (e.g., immature or ill-prepared for motherhood) of the pregnant woman. However, this position can still be used to support a theory of psychogenesis by suggesting that the etiology of HG is due to the pregnant woman's inability to cope with environmental stress. For example, Katon et al. (1980-81) contended that the hospitalized hyperemetic woman seeks a "time out" from a stressful world.

A number of psychological interventions have been advanced for treating patients diagnosed with HG, such as extended psychotherapy (Henker, 1976), brief psychotherapy (Zechnich & Hammer, 1982), hypnosis (Baram, 1995; Fuchs, Paldi, Abramovici, & Peretz, 1980; Klaus, 1995; Kroger & DeLee, 1946; Torem, 1994), behavior modification (Callahan et al., 1986), relaxation training (Simone & Long, 1985), and biofeedback (W. Barcy, personal communication, October 25, 1990).



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### Psychogenic Etiology: A Historical Overview

The majority of the literature has been published by male physicians primarily in the medical specialties of obstetrics and family practice. Fairweather (1968) provided an extensive historical review of NVP, noting documentation of vomiting in an Egyptian papyrus dated 2000 B.C., by Hippocrates some 1,700 years later, and in an early Greek obstetric reference entitled Soranus' Gynecology, written by the early second-century Roman physician, Soranus. Historically, HG was a significant cause of maternal deaths (Sheehan, 1939; Tillman, 1934). The prevailing belief among early physicians was that HG was a biologically based illness to be taken seriously.

In the early twentieth century, numerous diagnostic classifications of HG were proposed, which included psychiatric factors. For example, a popular obstetric text distinguished between two types of pernicious vomiting: neurotic and toxemic (Williams, 1923). Neurotic vomiting was viewed as the more common of the two and treatable by suggestion to alleviate the "nervous condition" (Williams, 1923, p. 579). The toxemic type was considered very serious, with a rapid course and grave prognosis. The condition was often fatal; attempts to induce abortion in order to save the life of the woman were often performed too late. Williams stated, "A certain proportion of cases will die no matter what may be done" (p. 585). DeLee and Greenhill (1943) questioned the classification of HG as a toxemia yet noted three classes of HG: (a) the main symptom of toxicosis, (b) functional neurosis or psychosis, and (c) some disorder of the gastrointestinal or urinary tract (p. 354).

At least two primary factors have influenced medicine's explanation for a psychogenic etiology of HG. First, the use of modern intravenous-fluid therapy for NVP and HG occurred some time between its introduction for adult patients in the 1920s (Zimmerman & Strauss, 1989) and for pregnant patients around 1945 (Eller & Randall, 1945). Intravenous-fluid hydration therapy addressed the issue of dehydration and helped to keep women alive, but it did not necessarily stop the nausea and vomiting associated with HG. Once the concerns of dehydration were addressed and maternal morbidity and mortality were no longer a primary concern, HG was viewed more as a nuisance, and psychodynamic theories were looked to for explanations for this illness.

Second, psychoanalytic theory was gaining popularity at about the same time that medicine advanced the discovery of intravenous-fluid therapy. A specific branch of medicine--psychiatry--then began to address the issue of the origins of HG. In their historical analysis of beliefs regarding NVP (including some HG literature) that parallels the HG literature, O'Brien and Newton (1991) documented this attitudinal shift as one from the Somatic era (until 1920) to the Intrapsychic era (1930-1980). The authors described the evolution into our current prevailing theory of etiology of NVP as the Metabolic and Social Stress era (1981-present).

Opposition to the psychogenic explanation arose as early as 1929, when Peckham cautioned physicians to avoid assuming a neurotic element for fear of overlooking a potentially dangerous physiological condition. He concluded that it is difficult to conceive a neurotic etiology in patients who begin to vomit before a menstrual period has been missed. In a 1946 study of 85 German women applying for

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abortion, none of whom developed HG, Nordmeyer argued against a psychogenic etiology, concluding that one would expect to find HG in this population of women in whom psychological factors were present (Harvey & Sherfey, 1954). Majerus et al. (1960) found no significant differences between vomiters and controls to suggest any association between HG and chronic psychiatric or psychologic disorders. Interestingly, this early opposition to assuming a psychogenic etiology has been virtually ignored in the literature. Disregard for alternative explanations for HG is most likely due to the aforementioned psychological theories and social and cultural climate of the period.

Recently, modern theories of human development have begun to challenge preexisting theories. Theories of adult human development have emerged that have shifted our understanding of the psychology of women (Berzoff, 1989; Gilligan, 1982). For example, developmental theorists now view ambivalence in the first and second trimesters as a normal and expected aspect of the developmental and maturational processes of pregnancy (Nadelson & Notman, 1990). In contrast to traditional psychoanalytic theory that views ambivalence in pregnancy as a sign of immaturity and psychopathology and assumes psychogenic causality, a developmental framework postulates that ambivalence may cause HG, may be one of many contributing factors, or may be a separate and unrelated entity that has no relevant impact on the illness.

In addition to human development theories, innovations in medical technology have influenced, albeit ever so slightly, dominant theories of psychogenesis. There is a trend toward a more aggressive treatment approach to HG which utilizes invasive medical interventions such as Total Parenteral Nutrition (TPN). This has led to a

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recent surge of research in the medical subspecialty of nutrition, with the primary aim of improved pregnancy and infant outcomes (Newman, Fullerton, & Anderson, 1993). Although not the original intention, some nutrition (Abell & Riely, 1992) and nursing researchers (Long & Russell, 1993) have challenged the assumptions of HG as a psychosomatic illness. For example, their use of language does not assume a psychogenic etiology, they described the common emotional and psychologic responses resulting from pregnancy complications rather than reporting these reactions as the causal explanation, and they documented clinical observations of medicine's general lack of empathy toward HG patients.

Also, feminist scholars have argued that research designs are often constructed merely to confirm preexisting gender stereotypes. For example, Rothman (1991) criticized designs based on retrospective studies that found women suffering from severe nausea of pregnancy as more ambivalent about their pregnancies than women who do not experience severe nausea. She concluded, "It is as if these studies were designed to prove that the attitudes *cause* the physical condition, such as nausea" (p. 250). Rothman argued that prospective studies that start with women's beliefs and attitudes may more accurately portray the relationship, if any, between nausea and ambivalence. That is to say, being ambivalent about pregnancy may cause one to become sick; however, it is also plausible that experiencing severe physical sickness during pregnancy causes one to feel ambivalent.

Over the years, physicians and other health care professionals have offered a variety of recommendations on how best to interact with the HG patient. A supportive

approach was described by Peckham (1929). He recommended that physicians rule out a physical cause for the vomiting, sensitively inquire about possible fears or personal problems that may be affecting the patient, and provide reassurance without minimizing the patient's illness experience.

In contrast, the belief that HG is a psychosomatic disorder has contributed to a variety of punitive approaches toward the care of the hospitalized patient. Atlee (1934) ordered patients to have no contact with their husbands or families for the first 48 hours of hospitalization and instructed nurses that patients were not to be given a "vomit bowl," but must vomit in bed. Moreover, he stated that "the nurse is instructed to be in no hurry about changing her" (p. 757). Others encouraged the physician to purposely invoke the element of fear, with "treatment rendered so harsh and painful that the patient stops vomiting to effect its discontinuance" (DeLee & Greenhill, 1943). For example, Williams (1923) agreed that pernicious vomiting was a manifestation of neurosis, based on his clinical observation that women with HG spontaneously improve with the physician's threat of induced abortion or after the application of leeches to various parts of the body. Walton (1973) recommended nursing strategies that included removing the "vomit bowl" from the patient's view (based on the assumption that if the bowl is out of sight the patient will not think of vomiting) and the withholding of "too much sympathy" for the patient's plight (p. 453).

As early as 1945, clinicians and scholars became interested in the diagnosis of HG after observing the various punitive attitudes and behaviors by some health care professionals (Tylden, 1968). Despite this documented shock and disapproval, many



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of these attitudes and behaviors still exist some 45 years later (Munch, 1991). Furthermore, some have contended that the presumption of psychopathology and the practice of an automatic psychiatric referral for women hospitalized with HG may actually increase patients' distress (O'Brien & Zhou, 1995).

Medicine has a tendency to adhere to a deterministic view that every effect has a cause and that the cause can be identified (Marantz, 1990). Therefore, because medicine has been unable to establish the underlying pathophysiological mechanism of HG or a definitive treatment, it tends to assume a psychological etiology. Nadelson and Notman (1990) argued that labeling reproductive disorders and related phenomena psychogenic in the absence of clear data "is a simplistic and reductionistic approach to a complex process. It is supported by the need to resolve ambiguity and maintain an illusion of knowledge" (p. 1).

In sum, the presumption of a psychogenic etiology has persisted for decades despite growing doubts and little evidence that psychologic factors cause HG (Lennane & Lennane, 1973; Neri et al., 1995; Rosen, 1955). Although the exact cause of HG remains unknown (Anderson, 1994), some contemporary authors have begun to conclude that the etiology is most likely multifactorial and that the manifestation of the illness may differ among patients (Callahan et al., 1986; Cowan, 1996).

### The Patient-Doctor Relationship

This researcher investigated women's health care in the treatment of HG within the context of the patient-doctor relationship. Four dimensions of the relationship are discussed in this section: an overview of the patient-doctor relationship, physicians'

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attitudes toward patients, patients' expectations, and physiological and psychological effects.

### Overview

The patient-physician relationship was the primary therapeutic intervention during premodern days (Novack, 1987). The doctor's "bedside manner" was often all that could be offered the patient. In the fourth century B.C., Hippocrates wrote about the importance of the physician's sensitivity as treatment that positively influenced patients' recovery (DiMatteo, 1979) and asserted that patients who were satisfied with their doctors might recover from serious illness (Novack, 1987).

Once viewed as a vital aspect of the healing process in and of itself, the patient-doctor relationship now is characterized as having two distinct dimensions. Instrumental or technical aspects of medical care are deemed the "science" of medicine; the expressive or affective and socioemotional components are deemed the "art" (DiMatteo, 1979). Technological advances led to a focus on the science, to the neglect of the interpersonal. Good (1994) asserted that the psychosocial dimensions of medicine have been marginalized within the field.

Despite medicine's technological advances, the American Medical Association (AMA) Code (Reiser, 1991) reflects the position that respect for the dignity of patients, in addition to technical competence, is required in an ethical patient-doctor relationship. In practice, there have been attempts to rectify the problem of the marginalization of the psychosocial dimensions of medicine. For example, innovative medical education

programs that teach humanistic interpersonal skills are being developed (Hendrie & Lloyd, 1990; Novack, 1987; Spiro, 1992).

### Physicians' Attitudes Toward Patients

Doctors' affective responses toward particular patients or patient groups can be as important as their medical knowledge in determining treatment decisions. Medical decisions are based on both cognitive (e.g., knowledge and expertise) and noncognitive (e.g., affective and sociological) factors (Epstein et al., 1993). Hardin and Hailey (1993) noted that negative attitudes held by health care professionals lead to less responsive or favorable interactions with their patients. Similarly, Jones and Morrell (1995) found that a positive interpersonal relationship was related to doctors' increased availability to patients and their willingness to refer patients to a specialist in order to preserve the relationship.

In addition, there is some evidence to suggest that physicians like their healthy patients more than their unhealthy ones (Hall, Epstein, DeCiantis, & McNeil, 1993). One might speculate that this may be a result of physicians' feelings of helplessness or merely their intolerance for dependent, needy patients who require extra time and attention. Gordon (1983) contended that physicians often act "brusquely" when they are not able to satisfy their patients' needs; this behavior is often a defense mechanism that arises out of the frustration doctors experience when their medical knowledge is inadequate. Moreover, the reality of the day-to-day demands of clinical practice poses significant constraints on physicians' time, energy, and capacity for empathy (West, 1984).

In particular, the health care team's emotional reactions to women experiencing pregnancy complications can become intensified as a result of the inherent stress of an uncertain outcome, the complex emotional response of the high-risk pregnant patient, and the presence of two patients in obstetric care--the woman and the fetus (Wohlreich, 1986). Wohlreich observed that physicians may become annoyed by a woman who has "difficulties" adjusting to the medical regimen and/or hospitalization; physicians may also experience guilt when subjecting patients to uncomfortable treatment in order to save the fetuses. In addition, the author identified that it is not uncommon for health care providers to become alarmed at a woman's expression of ambivalence about her pregnancy; they may respond in nonproductive ways by becoming annoyed, withdrawing from the patient, labeling the patient "crazy," or trying to cheer her up. Similarly, Katz (1984) contended that some physicians psychologically abandon their patients by withdrawing "behind a curtain of silence or evasion" (p. 206); this unintentional, psychological abandonment may affect a patient's physiological and psychological health as well as her willingness to comply with medical recommendations.

### Patients' Expectations

A variety of patient sociodemographic and personality characteristics influence their particular expectations of the patient-doctor relationship. Despite individual differences, the literature suggests that in addition to expecting expert medical care, patients tend to prefer doctors who demonstrate humanistic characteristics. Generally, patients want doctors who take their symptoms seriously, listen and ask questions about

their symptoms, treat them like people and not only as patients, and take a personal interest in aspects of their lives other than the disease (Arborelius & Bremberg, 1992). Empathic interaction, involving the understanding of a person's feelings and the communication of that understanding (Rogers, 1957), by the physician is preferred by patients. In an extensive literature review, Frankel (1995) reported that empathy is related to outcomes of patient satisfaction, patient adherence to the treatment plan, and medical malpractice. Furthermore, many patients desire to discuss with their physicians problems arising from and affected by the illness condition (e.g., employment, finances, childrearing). Unfortunately, contextual concerns such as these are often neglected in the medical discourse of the patient-doctor encounter (Waitzkin, 1991).

### Physiological and Psychological Effects

There is some documentation suggesting that physicians' interpersonal behaviors toward the acutely ill can influence patients' physiological outcomes (DiMatteo, 1979; Kaplan et al., 1989), postsurgical recovery (DiMatteo & Hays, 1980), and psychological condition (Wolf, Putnam, James, & Stiles, 1978). In a Finland study, Jarvinen (1955) found that the emotional stress of physician rounds may have deleterious, and potentially fatal, effects on cardiac patients. He concluded that a calm and sympathetic manner in addition to careful attention to the phrasing of the physician's words when providing information can positively affect the patient's health status. Kaplan et al. found that more patient (and less physician) controlling behaviors, more positive physician affect, and more information-giving provided by the physician were related

to better patient health status as measured by physiological indicators, functional status, and patients' perceptions of overall health status.

Thus, in addition to medical treatment, the natural course of the disease process and the spontaneous recovery from illness, the interpersonal interaction of the patient-physician encounter can be characterized as a placebo that contributes to the healing process and should be regarded as a primary therapeutic tool (Brody, 1992). The patient-physician relationship may be a factor in decreasing patients' anxiety, increasing patients' feelings of well-being, and promoting recovery from illness. In essence, the patient-doctor relationship is the foundation of the medical encounter and should be handled with the greatest of care and mutual respect. This human relationship remains even when technological interventions aimed at combating illness and disease fall short or fail.

Similarly, patient-centered care has been advocated as a model of the patient-doctor relationship more advantageous than the traditional doctor-centered style. Patient-centered care refers to the process whereby the physician seeks to establish a health partnership (Keller & Carroll, 1994); both physician and patient explore their ideas and beliefs about the presenting problem and develop a mutually agreed upon treatment plan based on a shared agreement about the nature of the problem (Seale & Pattison, 1994). When doctors define an illness differently from their patients, they may miss the meaning of the illness experience as perceived by the patients (Roter & Hall, 1992). Stories about the nature of the ailment and the plan of action that are mutually



constructed by both physician and patient can provide a comforting quality to the patient (Brody, 1987; Ventres, 1994).

Moreover, the importance of a patient-centered-care approach by the physician may improve both patient health outcomes and satisfaction (Bass et al., 1986; Brody, 1992; Seale & Pattison, 1994). Symptom relief has been found to be associated with patients' perceptions that they and their physicians agreed about the nature of the problem (Bass et al., 1986). Assuming, then, that patients' primary goal for seeking medical care is relief of symptoms, there is related research to suggest that patients are most satisfied with their doctors when they and their doctors share the same explanatory model of the illness.

### Patient Satisfaction

A trend toward asking patients their opinions regarding their attitudes toward physicians and health care in general arose in the late 1960s and early 1970s, with a gradual shift toward asking patients specifically about their own physicians (Hulka, Zyzanski, Cassel, & Thompson, 1970). Previous indicators of quality health care were mortality, morbidity, and cost. Currently, patient satisfaction has joined these indicators and is recognized by health care providers as a legitimate measure of health care quality (Ross, Steward, & Sinacore, 1995). Large health maintenance organizations (HMOs) are beginning to use measures of patient satisfaction as criteria for physician pay (Arnold & Forrow, 1990). And psychosocial training programs in medical schools are beginning to use patient satisfaction as a key outcome measure (Smith et al., 1995).

Simply put, patient satisfaction is defined as "a patient's attitudes toward health care received" (Hsieh & Kagle, 1991). Patient satisfaction is, however, a multidimensional construct encompassing aspects including (but not limited to) personal characteristics, health status, health plan, mode of delivery of service, and patient expectations (Hsieh & Kagle, 1991; Kenny, 1995; Like & Zyzanski, 1987; Ware et al., 1983). A number of patient satisfaction instruments have been developed and are continually being evaluated and revised (Ross et al., 1995; vanCampen, Sixma, Friele, Kerssens, & Peters, 1995). Patient satisfaction is important in that it has been found to be associated with patient adherence to the medical regimen (Zisook & Gammon, 1980-81), improved health status (Hauck et al., 1990), and malpractice suits (Vacarinno, 1977). Dissatisfaction with care appears to be related to "doctor shopping" (DiMatteo et al., 1980), which may lead to increased medical costs as duplication of services and procedures tends to occur.

The literature suggests that perhaps the more cogent and compelling factor in patients' satisfaction with their health care and the patient-physician relationship, in particular, is what patients perceive. For example, in a study on patients' perceptions of humanism in physicians and the effects on positive health behaviors, Hauck et al. (1990) asserted that patients' perceptions of the patient-physician relationship "would more accurately reflect the patient's experience and be best correlated with treatment outcomes . . . [because] questionnaires in which physicians rate their personal reactions to statements and hypothetical situations do not necessarily accurately reflect their behavior as experienced by patients" (p. 448). There is also evidence to suggest that

physicians tend to both overestimate their communication skills and patients' satisfaction with their services (Hauck et al., 1990), and underestimate the degree of patient satisfaction (Shore & Franks, 1986). Moreover, doctors tend to rank the determinants of patient satisfaction differently from patients. Kenny (1995) concluded that "patient perceptions accurately reflect actual physician behaviours" (p. 435).

There is evidence that patients are concerned with both the technical and interpersonal skills of their physicians (Falvo & Smith, 1983), although patients' perceptions of nontechnical interventions were found to be better predictors of patient satisfaction (Brody et al., 1989). Furthermore, the emotional support that patients receive from their doctors significantly influences their judgment of the doctors' competence (DiMatteo, 1979). This suggests that patients tend to first evaluate the affective care and then generalize to their assessment of the physicians' technical competence (DiMatteo & Hays, 1980). In addition, differences in patient and doctor perceptions of and expectations for relational support in the patient-doctor relationship may lead to dissatisfaction with health care (Anderson & Zimmerman, 1993; Cegala et al., 1995).

### Summary

In Chapter II, the relevant literature was discussed in terms of four broad topics. They were women's health and gender bias, hyperemesis gravidarum, the patient-doctor relationship, and patient satisfaction. Relevant subtopics also were presented. The methodology used in the study is presented in Chapter III.

In this dissertation, women's own beliefs and attitudes and their perceptions of their doctors' beliefs and attitudes about HG were examined as a means for understanding the elements of the patient-doctor relationship that affect patients' satisfaction with the medical care received from their doctors. In addition, particular aspects of women's lived experiences with HG that helped to shape their perceptions of the patient-doctor relationship were analyzed as a first step to giving voice to this patient population that has not been completely represented in the existing literature.

## CHAPTER III

### METHODOLOGY

#### Epistemology and Methodology

The branch of philosophy that is concerned with questions of what can and cannot be known is epistemology (Shaffer, 1971). Literally speaking, epistemology is the theory of knowledge. What counts as knowledge and how knowledge is produced have been topics of intellectual discourse for centuries. The epistemology of a discipline is characterized by the way it conceptualizes problems (the problematic), the sources of evidence, and the methods of analysis and inference (Hahn, 1995). Moreover, scholars conduct research based on their assumptions about people and the ways in which social reality is constructed. Knowledge of the researcher's methodological stance, then, is essential in understanding all aspects of the research, from hypothesis generation to data analysis and conclusions.

The present study was based on an assumption of feminist empiricism that mainstream inquiry has not adhered rigorously enough to its own norms; the practice of the scientific method has been incomplete as a result of sexist and androcentric biases (Harding, 1987). One contrast between feminist and traditional methodologies is that the questions that are asked (and not asked) in feminist research "are at least as determinative of the adequacy of our total picture as are any answers that we can

discover" (Harding, 1987, p. 7). Malterud (1993), a family practice physician in Norway, remarked, "Unfortunately, women's voices are often silent in the factory where medical knowledge is produced" (p. 365). This author pushed for the "construction of a feminist medical epistemology--a path toward medical knowledge that reflects women's reality" (p. 371). Similarly, Todd (1989) suggested that "physicians and patients bring to their meetings with each other unexamined, deeply entrenched assumptions about the world and therefore about medical care" (p. 102). Constructing the story from the perspective of marginalized groups might generate less partial and distorted accounts of social relations (Harding, 1991).

Methodologically speaking, studying women is not new. What is new is the study of women from the perspective of their own experiences; the practice of "studying up" versus "studying down" is new in the gender literature (Harding, 1987). For example, physicians have been studying the "peculiar" behaviors of women with premenstrual syndrome, but women are only now beginning to study the peculiar characteristics of physicians and the nature of their interactions with women patients. The problematizing of women's experiences as acceptable issues and sources of answers is a practice unique to feminist research (Allen & Baber, 1992) and is deemed appropriate for the discipline of social work (Davis, 1986; Sands & Nuccio, 1992; Swigonski, 1993). In addition, conducting research *for* women rather than *on* women alters the purpose of research from one that primarily seeks knowledge generation to one that attempts to conduct research in the interest of women. Feminist inquiry,

consistent with social work values, aims to empower women by helping them to understand and to connect their experiences to the larger social context.

This study was guided by various feminist epistemological and methodological principles of conducting research. The researcher attempted to challenge prevailing concepts in the traditional hyperemesis literature and to shift the discourse by asking new questions about women who have experienced the pregnancy complication of HG. Unlike previous HG studies, it is the perceptions and the experiences of the women-patients living with HG that is of interest in this inquiry. Moreover, the study incorporates principles of accountability not only to the discipline, but to the respondents. For example, all respondents will be provided a summary of the study findings.

In this dissertation, both quantitative and qualitative research methodologies were used to understand women's experience with HG and various aspects of the patient-physician relationship as it pertains to patient satisfaction. The study is exploratory to the extent that it was focused on discovering answers to certain questions. For example, there is no documentation in the literature regarding patients' perceptions about their own and their doctors' beliefs about HG. The study is also explanatory, however, in that an attempt was made to account for the salient factors affecting patients' reports of satisfaction with the medical care received from their doctors.

The goal of qualitative research is the identification of common themes and primary patterns in the data (Patton, 1987) and to give voice to the participants. In this

study, qualitative data were gathered through the use of standardized, open-ended questions. The data were used to illustrate and clarify quantitatively derived findings and related patterns and themes. The open-ended questions were approached primarily from a deductive design. This design is indicated when "the researcher has good prior acquaintance with the setting, has a good bank of applicable, well-delineated concepts, and takes a more explanatory and/or confirmatory stance involving multiple, comparable cases" (Huberman & Miles, 1994, p. 431). The probes within each question, however, were used for both clarification and exploratory purposes. The open-ended questions were biographical in nature (Strauss & Corbin, 1990) and shed light on specific aspects of women's experience with HG and the patient-physician relationship.

### Subjects and Sampling

The setting of this study was a 529-bed tertiary-care hospital that provides both high-risk obstetric and neonatal intensive care services. This regional perinatal center services 13 counties, encompassing both urban and rural settings, and is located in a large city in western Michigan. The study sample was drawn from the population of HG patients at this hospital. It consisted of a census of all available patients hospitalized for HG from January 1993 through April 1997 who (a) were currently pregnant and had at least one inpatient hospitalization on the high-risk obstetric unit, but whose HG was resolved and/or (b) had given birth since 1993 and had experienced at least one inpatient hospitalization because of HG during that pregnancy. In cases in which a woman had had more than one HG pregnancy since 1993, the most recent HG pregnancy was the specified unit of investigation. Those eligible for the study were



either patients or former patients of this hospital who were alert and oriented to person, place and time, had no identifiable diagnosis of mental illness, could speak English, were at least 20 years of age at the time of their inpatient hospitalization, and could be reached by telephone. The decision to exclude adolescents was made so as to narrow the focus of the study to adult women respondents. Approval to conduct the study was received from the Research and Human Subjects Committee at this hospital and from the Michigan State University Committee on Research Involving Human Subjects (UCRIHS). The obstetrician-gynecologists and the Director of the Women's Hospital at this specified hospital were informed of the nature of the study.

Potential respondents were recruited for the study in the following manner. A list of the names of patients hospitalized for HG at the hospital from January 1993 through April 1997 was obtained from the hospital's medical records department. After eligible subjects were identified, the primary investigator and research assistant contacted each prospective respondent by telephone to explain the study, obtain verbal agreement to participate in the study, and schedule an appointment for the telephone interview. In some cases, the respondents agreed to conduct the interview at the time of the initial contact. The sampling strategy was such that attempts to contact every eligible patient from January 1993 through April 1997 occurred during the seven-week data-collection period from June 16 to August 8, 1997.

The sample consisted of 163 patients hospitalized for HG from January 1993 through April 1997. There were 24 not eligible for reasons of age and language. An additional 36 women could not be located due to invalid telephone number, phone

disconnection, and the possibilities of relocation, work schedule, and vacation. Of the 103 who were eligible, initial verbal consent was obtained from four women, although the interview did not take place after numerous attempts to reconnect, and three women declined to participate due to time constraints. Of the 103 women eligible, 96 (93%) participated in the study (59% of all HG patients hospitalized).

For the purpose of this dissertation, a decision was made to exclude outpatients, that is, HG women who were only treated by and released from the emergency department. After reviewing the emergency department HG patient list and consulting with obstetrician-gynecologists, there was some question as to the possibility that some women diagnosed with HG during a brief emergency department visit may have been ill with a gastrointestinal flu, for example, and not true HG. Obtaining respondents from only the inpatient hospital pool (many of whom were also treated in the emergency department) provided a greater level of consistency in diagnosis; hospitalized women clearly met the diagnostic criteria for the medical diagnosis of HG as determined by the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM; Practice Management Information Corporation, 1997). Moreover, using hospitalized women controlled for, to some extent, severity of illness. The researcher assumed that women hospitalized with HG tend to exhibit more severe symptoms than those treated solely as outpatients.

### Procedure

The study was based on a retrospective, ex post facto research design using questionnaires. Information was gathered through the administration of a structured telephone survey that incorporated open-ended questions. The interview focused on discovering the relationship between patient perception factors most highly associated with patient satisfaction. The telephone interview method was a convenient method as some respondents lived many miles from the hospital. Also, it was thought that perhaps an anonymous voice may have allowed the respondents a greater sense of freedom to ventilate their opinions (O'Brien & Naber, 1992).

Respondents who provided verbal agreement were mailed two copies of the consent form (Appendix A), cover letter (Appendix B), and a return-addressed, stamped envelope and were asked to return one set to the investigator and keep one for their records. Attempts were made to secure the signed, written consent form. In the event that the investigator did not receive the signed consent form, the study proceeded based on verbal telephone consent at the prescheduled telephone appointment time (per Human Subjects approval). At the time of the telephone interview, the investigator confirmed that the respondent had received and read the consent form, and briefly reviewed the components of the consent form.

Women in the study participated in one 20- to 30-minute structured telephone interview that incorporated open-ended questions. Only the open-ended questions were tape-recorded with verbal consent of the respondent. The order of the interview was as follows (Appendices C through E): (a) Hyperemesis Questionnaire: closed-ended

questions, (b) CSQ-8, (c) Humanism Scale, (d) Hyperemesis Questionnaire: open-ended questions. The HG pregnancy of interest was clearly identified to the respondent based on the date of the hospitalization. Respondents were asked to answer interview questions based on their entire HG illness experience, and not only their hospital experience. Thus, the study was not limited to patients' perceptions of their hospital experience but encompassed the entire course of HG, including both inpatient and outpatient medical care.

### Instrumentation

The following dependent and independent variables were examined. The dependent variable was a patient's satisfaction with the medical care received from her doctor. The five independent variables were:

1. Causal Explanation: Patients' perceptions of their doctors' beliefs about the causal explanations of the HG.
  - Causal I: Beliefs about the etiology of HG in general.
  - Causal II: Personal attribution--beliefs about a particular respondent's HG.
2. Seriousness: Patients' perceptions of their doctors' beliefs about the degree of seriousness of the HG.
3. Impact: Patients' perceptions of their doctors' beliefs about the impact of the HG on the patients' lives.
4. Congruence: The extent to which patients' own beliefs and their perceptions of their doctors' beliefs about the causal explanations of HG,

the degree of seriousness, and the impact on the patients' lives were shared.

5. Humanism: Patients' perceptions of their physicians' humanism.

Various demographic variables also were examined in terms of their relationship to the dependent variable as they provided additional explanatory information. Following is a summary of the specific instruments that were used to measure the independent and dependent variables.

Hyperemesis Questionnaire

A 108-item questionnaire (Appendix C) designed to obtain information regarding particular aspects of patients' experience with HG, and to assess aspects of patients' own beliefs and their perceptions of their doctors' beliefs about HG and the illness experience, was developed based on a review of the literature and clinical experience (Munch, 1997). Respondents were instructed to answer the questions based on their current or most recent pregnancy in which they were diagnosed with HG. They were instructed to think about only the time period when they were sick with HG (vs. their entire pregnancy), and to think about only the doctor who took care of them the most during that time period. In an attempt to control for response bias, respondents were prompted throughout the interview with statements such as, "This is not a test of what you know," "There are no right or wrong answers to any of these questions," and "It is your opinion about your experience that is important in this study."

The Hyperemesis Questionnaire was developed by the researcher specifically for use in this study. Face validity was tested by having six external reviewers read and

critique the questionnaire; practice interviews occurred with an additional three people. Reviewers were hospital-based health care practitioners in the fields of nursing and social work. Changes in the wording and phrasing of the questionnaire for clarity purposes were incorporated based on the reviewers' comments. Interviewer bias was controlled for, in part, by standardizing the interview procedures. Also, extensive training of the research assistant by the primary investigator and frequent meetings between the two occurred to enable appropriate standardization of data collection and data analysis. The components of the instrument are described in the following paragraphs.

Demographic information. Thirty items encompass questions such as socioeconomic status, pregnancy and birth information, HG information, and background information regarding the patient's doctor. Although demographic variables were not specifically identified in the research hypotheses, it was anticipated that exploratory analyses would be conducted examining various relationships of interest.

Scales. Three scales comprise 20 statements about patients' own beliefs and perceptions about the illness experience. The scales were derived based on the aforementioned women's health literature and clinical observation of a tendency for women's illness complaints to be attributed to psychosomatic factors and, therefore, minimized by physicians. Specific factors pertinent to scale development in this study were based on illness perception, doctor-patient relationship, and patient satisfaction literature. This literature incorporates attitudes and beliefs about the etiology of an

illness, the severity of symptoms, and the extent to which the illness affects a patient's life (Arborelius & Bremberg, 1992; Curbow, Andrews, & Burke, 1986; Kenny, 1995; Liao, Hunter, & White, 1994; vanDulmen, Fennis, Mekkink, vanderVelden, & Bleijenberg, 1994; Weinman, Petrie, Moss-Morris, & Horne, 1996).

HG Questionnaire scales are based on a 4-point Likert scale without the neutral position, ranging from responses of *strongly disagree* (1) to *strongly agree* (4). The same 20 statements are then rephrased and repeated to address respondents' thoughts about their doctors' beliefs and perceptions during their treatment for HG. Reliability coefficients were obtained for each of the scales of the HG Questionnaire (Table 1).

Table 1

Internal Consistency (Cronbach Alphas) for Hyperemesis Questionnaire Scales: Patients' Perceptions of Doctors' Beliefs and Patients' Beliefs

| Scale                           | Reliability Coefficient |                 | Number of Items |
|---------------------------------|-------------------------|-----------------|-----------------|
|                                 | Doctor Beliefs          | Patient Beliefs |                 |
| Causal Explanation: Total       | .7519                   | .6280           | 9               |
| Causal I: General               | .3169                   | .0207           | 5               |
| Causal II: Personal Attribution | .8727                   | .7989           | 4               |
| Seriousness                     | .8609                   | .7668           | 6               |
| Impact                          | .8276                   | .7397           | 4               |

Note.  $N = 96$ .

The scales of the HG Questionnaire are described as follows:

1. **Causal Explanation scale.** This scale consists of 10 items (Questions 1-10) representing beliefs about the etiology of HG, such as physiological, genetic, psychological, and environmental causes. In later analyses, the scale is broken down into two subscales: Causal I: General and Causal II: Personal Attribution. The scale is also analyzed in its combined form, Total Causal. Causal I consists of six items that asked about HG in general (i.e., "Hyperemesis is mostly caused by stress."). Items 2 and 3 were reverse-scored. Causal II consists of four reverse-scored items that address ways in which the illness might be attributed to a particular patient (i.e., "I could have prevented getting hyperemesis."). Item 6, "The cause of hyperemesis is not known," is purely an exploratory question; it is not included in later analyses because the nature of the question is nondirectional.

2. **Seriousness scale.** This scale consists of six items (Questions 11-16) representing beliefs about the degree of seriousness of the HG (e.g., "My hyperemesis was a serious condition.").

3. **Impact scale.** This scale consists of six items (Questions 17-20) representing beliefs about the extent to which HG affected a patient's life (e.g., "I participated in fewer social activities because I had hyperemesis.").

Open-ended questions. The qualitative portion of the questionnaire consists of a standardized interview based on six open-ended questions. These questions focus on patients' expectations of the illness course, the patient-doctor relationship, and any additional information that respondents desire to share.



### **Humanism Scale**

The Humanism Scale (based on the Physician Humanism Scale by Abbott, 1983) developed in 1985 by Fern Hauck, MD, MS (Hauck et al., 1990, p. 447), is a 24-item instrument designed to measure patients' perceptions of the humanistic behaviors of their physicians or health care providers. The definition of humanism was based on a synthesis of the literature and comprised the following eight components of physicians' or health care providers' behavior:

1. Respects patient's viewpoints and considers his or her opinions when determining health care decisions.
2. Attends to the psychological well-being of the patient.
3. Regards the patient as a unique individual.
4. Treats the patient in the context of his or her family and social and physical environment.
5. Possesses good communication and listening skills.
6. Engenders trust and confidence.
7. Demonstrates warmth and compassion.
8. Is empathetic.

The Humanism Scale was originally used as a self-administered mail questionnaire based on a Likert scale in which respondents mark an "X" on the line to tell how strongly they agree or disagree. Responses range from *strongly disagree* to *strongly agree*; possible scores for each item and the mean variable scores are 1 to 99. Questions 8, 9, 13, and 16 are negative items. Hauck et al. (1990) found a reliability

coefficient of the 24 humanism items, as determined by Cronbach's alpha, of .95. In addition, they reported that physician humanism scores ranged from 16 to 99, with a mean of 75; humanism explained 60.5% of the variance in patient satisfaction with physician-related aspects of care (e.g., doctor's skill/knowledge and interpersonal relationship skills as opposed to satisfaction with insurance issues or office hours, for example).

For the purposes of this dissertation, which used the telephone interview method, the scale was modified based on item categories of *strongly disagree* to *strongly agree*, with a 5-point anchored response with a neutral position. Also, the sentence structure was modified to read in the past tense because of the retrospective nature of the study. Cronbach's alpha for the Humanism Scale in this study was .9497, which is consistent with .95 reported by Hauck et al. (1990).

In analyzing both the quantitative and qualitative data in this study, some responses involving physician humanism raised questions about the validity of the scale. Caution should be taken not to overread why there might be merely agreement versus strong agreement about physician humanism reported, especially when respondents report high levels of satisfaction with the care received from their doctors.

For example, Questions 3, "I would bring up personal problems to my doctor," and 19, "I would talk to my doctor if something were bothering me," may have varied interpretations based on patients' expectations of the patient-doctor relationship (Like & Zyzanski, 1987). That is, some patients do not view their doctors as someone with whom they would share their personal problems, whereas others do. Thus, a patient's

expectations for the relationship may affect responses on the Humanism Scale, which does not necessarily reflect a perception of less physician humanism. In addition, when asked Question 15, "My doctor was able to put himself/herself in my shoes," many respondents chuckled and exclaimed, "He's a man, he can't understand." Again, lower scores reported by particular respondents on empathy items such as this may not necessarily mean that they viewed their male doctors as less humanistic. It is possible that these respondents did not expect their male physicians to be able to "put himself in my shoes" based on physician gender, yet they still reported satisfaction with care received.

#### Client/Patient Satisfaction Questionnaire (CSQ-8)

The Client/Patient Satisfaction Questionnaire, developed by Clifford Attkisson (Fischer & Corcoran, 1994), is a unidimensional, eight-item, 4-point anchored answer scale without the neutral position for assessing general client/patient satisfaction with health and mental health care services. The coefficient alpha for this established and frequently used measure of global satisfaction is .93 (Larsen, Attkisson, Hargreaves, & Nguyen, 1979). In addition, the internal consistency of the CSQ-8 has shown alphas ranging from .86 to .94 in a number of studies used with a variety of populations, appears to operate similarly across all ethnic groups, and has very good concurrent validity (Fischer & Corcoran, 1994). Scores on this measure have been found to be significantly related to client dropout rate, number of sessions attended, and clinical improvement as perceived by both clients and therapists (Attkisson & Zwick, 1982). Criticisms regarding the validity of the instrument have been that item phrasing with the

personal referent influences a socially desirable response set (Hays & Ware, 1986) and that operationalizing patient satisfaction as a unidimensional concept neglects to discriminate the various aspects within the concept (vanCampen et al., 1995).

With regard to these criticisms, item phrasing using a personal referent was deemed preferable in this study as it was the personal, specific perceptions of a woman's experience with HG and her perceptions of the patient-doctor relationship that were the units of investigation. Also, although other patient satisfaction instruments offer subscales that measure a variety of dimensions (e.g., interpersonal skills, technical skills, office wait time, payment issues, etc.) that can be useful in this type of research, a global rating of patient satisfaction was desired for the purpose of this dissertation.

In this study, medical care was defined as including both technical and interpersonal aspects of the physician's care for the following reasons. First, this study was primarily concerned with medical care that combines technical and interpersonal components of care integral to the patient-physician relationship; it was not directed at investigating the "business" of going to the doctor (e.g., satisfaction with waiting room time or insurance issues). Second, the Humanism Scale incorporates questions regarding both physicians' knowledge and technical skill, as well as interpersonal and socio-affective components. Thus, conceptually, both components were viewed as integral to the patient-doctor relationship. Moreover, analysis of this independent variable could be conducted on the separate dimensions if deemed necessary. Third, it was thought that the trend toward dichotomizing medical care into two distinct components (interpersonal and technical) may perpetuate the trend of marginalizing the

interpersonal aspects. That is, technical expertise is viewed as a given, whereas interpersonal skills are often viewed as optional rather than essential. This investigator assumed, then, that both technical skills and interpersonal skills are essential and inherent in the definition of medical care; therefore, patient satisfaction was measured by a global satisfaction scale.

Respondents in this study were instructed to consider the medical care they received from the doctor who took care of them the most during the course of their illness, and to answer the questions regarding only the care they received for their HG. For the purpose of this study, the sentence structure was modified slightly to reflect patients' general satisfaction with the medical care received from their doctors for HG. For instance, Question 1, was modified from "How would you rate the quality of service you have received?" to "How would you rate the quality of care you have received from your doctor?" Question 8 was modified from "If you were to seek help again, would you come back to our program?" to "If you were to seek medical care again for hyperemesis, would you go back to your doctor?" The instrument was changed to make it more specific (e.g., from "service" to "medical care received by your doctor"), and was checked for reliability. Cronbach's alpha for the Client/Patient Satisfaction Questionnaire in this study was .9384, which is within the range of .86 to .94 reported in previous studies.

## Data Analysis

### Quantitative

The goal of the analysis was to gain a better understanding of patients' beliefs, doctors' beliefs, shared beliefs, and physician humanism and their relationship to patient satisfaction. The computer software program, STATGRAPHICS *Plus* (STATGRAPHICS, 1995), was used to perform the majority of statistical procedures; SPSS (SPSS, 1996) was used to calculate Cronbach's alphas. Descriptive statistics were computed for each variable. Frequency distributions were computed for each variable of interest. There were only four missing items; four respondents declined to respond to the income question.

A new variable, Congruence, was created to determine the degree of perceived shared beliefs within patient-doctor pairs for all questions under the variables Causal Explanation, Seriousness, and Impact. The total congruence score is the sum of the absolute value of the differences between the patient and physician scores. A score of zero denotes perfect agreement. The congruence score does not describe the direction in which patients and doctors agree or disagree; it merely denotes the extent to which they share beliefs.

The normal probability and residual plots for each variable against Patient Satisfaction revealed that the probabilistic regression assumptions were not met (e.g., independent and identically distributed residuals). Therefore, nonparametric tests (e.g., Spearman rank correlation coefficient, Wilcoxon signed-rank) were appropriate tests

for these data. Spearman rank correlation coefficients were computed between the following independent variables and the dependent variable of Satisfaction:

1. Causal Explanation:

Total Causal (Items 1-10, excluding Item 6)

Causal I: General (Items 1-5, excluding Item 6)

Causal II: Personal Attribution (Items 7-10)

2. Seriousness

3. Impact

4. Congruence

5. Humanism

Analysis of the two subcomponents of Causal Explanation was conducted in order to explore any variations in perceptions about the etiology of HG for women in general and for the specific respondents in this study.

Significance was set at 1%. Because this researcher tested individually five independent variables against Patient Satisfaction, the conventional .05 rejection level was adjusted down to 1%, via the Bonferroni approach (Rosner, 1994; Snedecor & Cochran, 1989; G. Sturm, statistical consultant, personal communication, September 15, 1997), in order to have an overall level of 95% confidence after testing five hypotheses. That is, the more variables tested, the greater likelihood that a Type I error will occur (e.g., reject a true null hypothesis). Thus, setting the alpha at .01 provides greater assurance that any variable(s) found to be significant, after testing five, is most likely not due to chance.

The Wilcoxon signed rank test was applied to each of the items on the HG Questionnaire to calculate the statistical significance of the mean differences between doctors' and patients' beliefs. Negative values reflect higher patient belief scores compared to doctors' beliefs. Per the Bonferroni approach, significance was set at .0025 in order to have an overall level of 95% confidence after testing 20 items.

The reliabilities of the various components of the HG Questionnaire, the CSQ-8, and the Humanism Scale were measured using Cronbach's alpha statistic. Finally, various demographic variables were analyzed (using appropriate regression and analysis of variance [ANOVA] tests) to ensure that no confounding relationship existed with Patient Satisfaction.

### Qualitative

A content analysis was conducted to interpret and categorize data obtained with the open-ended questions. For the purpose of this dissertation, the initial phase in qualitative analysis, open coding, was conducted in order to understand the major themes and patterns that would inform the research hypotheses. More complex analyses of the rich data provided by the respondents, much of which went beyond the scope of this dissertation, will be conducted in the future. Further analysis (accomplished by techniques such as axial coding) relating more specifically the classes and categories that were found by open coding is necessary.

Open coding is the analytic process of naming and categorizing phenomena (Strauss & Corbin, 1990). The overarching theoretical classes were deductively derived based on the corresponding key variables of the study:



1. Causal Explanation
2. Seriousness
3. Impact
4. Congruence
5. Humanism

The dependent variable, Satisfaction, was not separately coded but is embedded in each of the five classes.

A list of themes or concepts, entitled categories, relating to each class was deductively derived from many of the interview items within each variable and/or the open-ended questions. For example, the four categories that comprise the HG Questionnaire items for the Seriousness scale (intensity, threat to patient, threat to baby, physician monitoring) were the categories used in analyzing the qualitative comments for the class: Seriousness.

There were also themes noted within some categories. These themes were inductively derived, developed by the primary investigator from the patterns that emerged from meanings respondents had attached to the data. An example is the theoretical class: Humanism. Qualitative comments were analyzed based on established categories of the operational definition of humanism proposed by Hauck et al. (1990). The preestablished category Engenders Trust and Confidence prompted "Believes Patient's Story" as one theme that emerged from participants' comments.

A codebook describing the operational definitions for each class and category was developed to address interrater reliability. In Phase I, a random sample of

transcripts was read, and notes related to the research questions were taken and discussed by the primary investigator and the research assistant in order to grasp an initial sense of the data. Phase I confirmed the strategy of using the deductively derived categories based on the research questions, and the quantitative items and open-ended questions on the HG Questionnaire. In Phase II, each sentence of every transcript was then analyzed to determine the appropriate higher and more abstract class of the six listed above, the categories within each class, and the themes within each category. The primary investigator read and coded every transcript and made the decisions regarding the final coding scheme. In an effort to verify the coding process, the researcher read the transcripts multiple times, continuously moving back and forth between the coding frame and the data. In this process, similarities and differences in the data were compared and questions were asked about the phenomena reflected in the data until the researcher was reasonably confident that the final coding frame accurately reflected the data.

#### Assumptions of the Study

The methodology was based on certain assumptions that, if violated, would affect the validity of the study. It was assumed, and there were no reasons to doubt, that the respondents were sufficiently knowledgeable to respond accurately about their experience with HG and would provide honest accounts of their experiences, perceptions, and feelings. Patients' retrospective reports of satisfaction with their doctors' care were assumed to correspond to their actual satisfaction at the time medical care was rendered. It was assumed that survey items would be clear enough for

respondents to answer the research questions. Finally, it was assumed that the findings of this study would be useful to the social work profession and to other disciplines such as medicine and nursing.

### Summary

Chapter III contained a discussion of the study's epistemology and methodology, subjects and sampling, procedure, instrumentation, data analysis, and assumptions. The results of the study are presented in Chapter IV, including the characteristics of respondents and physicians, general findings, and results by dependent variable and research hypothesis.

## CHAPTER IV

### RESULTS

#### Characteristics of Respondents and Physicians

This researcher examined the most recent hyperemesis gravidarum (HG) pregnancy for women hospitalized January 1993 through April 1997. Of the respondents, 31 described their 1993 pregnancy, 14 were pregnant in 1994, 16 were pregnant in 1995, 20 were pregnant in 1996, and 15 were pregnant in 1997. Of the 96 respondents, 83 (86.46%) had already given birth (including 4 pregnancies ending in fetal demise), and 13 (13.54%) were pregnant at the time of the interview. Four respondents (maternal transports) were transferred to the study hospital from hospitals within a 13-county radius.

At the time of their HG pregnancy of interest, the study respondents had a mean age of 27.65 years (range, 20-38 years; *SD* 4.23), a median education of some college/no degree, a median employment status of full time, and a median income category of \$30,000 to \$49,999 (range: < \$10,000 to > \$69,999). At that time, 86 (90%) were married, 8 (8%) were single/never married, and 2 (2%) were divorced. Seventy-three (76%) of the respondents were white, 16 (17%) Black/African American, 6 (6%) Hispanic, and 1 (1%) Asian/Pacific Islander.

The physicians of the respondents were 80 (83%) male and 16 (17%) female. Of these, 86 (90%) were white, 9 (9%) Black/African American, and 1 (1%) Hispanic. Obstetrician-gynecologists represented 81 (84.4%) of the physicians; 9 (9.4%) were perinatologists, 3 (3.1%) were in family practice, and 3 (3.1%) comprised other specialties (e.g., nutrition and nurse midwife). The median length of relationship (range: < 1 week to > 2 years) between the respondents and their doctors before being treated for HG was more than 2 years (43 respondents); 11 women were under their doctors' care for 1 to 2 years, 1 for 7 to 11 months, 22 for 2 to 6 months, 11 for 2 to 4 weeks, and 8 had known their doctors 1 week or less.

### General Findings

Findings will be presented by discussing each research hypothesis in terms of both its quantitative and qualitative findings. The qualitative data will be used to inform the quantitative results. Of the five independent variables tested using the Spearman rank correlation coefficient, Physician Humanism was the only independent variable found to have a positive, statistically significant relationship ( $r_s = .60$ ;  $p = .0000$ ) to the dependent variable, Patient Satisfaction. Potential confounding variables of interest were tested, and none was statistically significant. Despite the quantitative findings of no statistically significant associations between Patient Satisfaction and Causal Explanation, Seriousness, or Impact, the qualitative data suggested support for each of the hypotheses, including Humanism.

Table 2 contains the mean Likert scores of patients' own beliefs and their perceptions of their doctors' beliefs for each of the variables. Table 3 refers to the

Spearman rank correlation coefficients with Patient Satisfaction. Table 4 indicates the doctor-patient average difference for each item of the HG Questionnaire applied by the Wilcoxon signed rank test. Table 5 shows the demographic variables that were tested by either regression or ANOVA in order to rule out potential confounding variables. A histogram for Patient Satisfaction is presented in Figure 1. Figure 2 is the final coding frame for Physician Humanism.

### Results by Dependent Variable and Research Hypotheses

Table 2, representing the mean Likert scores of patients' own beliefs and their perceptions of their doctors' beliefs for each of the variables, will be discussed in the presentation of the dependent variable and each of the hypotheses that follows.

#### Patient Satisfaction

Values on the CSQ-8 ranged from 1 (*quite dissatisfied*) to 4 (*very satisfied*), with a total possible sum score of 32. Patient satisfaction scores ranged from the Likert values of 1.62 to 4, with a mean (Table 2) of 3.63 (actual values ranged from 12.96 to 32;  $M = 29.04$ ). This finding suggests that the respondents' mean score fell between *mostly satisfied* and *satisfied* with the medical care received from their doctors in the treatment of HG. Figure 1 shows that 91.67% of the mean satisfaction scores included values from 3 (*mostly satisfied*) on up through, and including, 4 (*very satisfied*).

Table 2

Comparison of Patients' Own and Their Perceptions of Their Doctors' Beliefs About Causal Explanation, Seriousness, and Impact on the Hyperemesis Questionnaire; Humanism; and Patient Satisfaction by Mean Likert Score, Median, and Standard Deviation

| Variable <sup>a</sup>        | Doctor Beliefs |            |           | Congruence |            |           | Patient Beliefs |            |           | Significance <sup>b</sup>    |
|------------------------------|----------------|------------|-----------|------------|------------|-----------|-----------------|------------|-----------|------------------------------|
|                              | <i>M</i>       | <i>Mdn</i> | <i>SD</i> | <i>M</i>   | <i>Mdn</i> | <i>SD</i> | <i>M</i>        | <i>Mdn</i> | <i>SD</i> |                              |
| Causal Explanation:<br>Total | 2.97           | 2.89       | .35       |            |            |           | 3.21            | 3.33       | .35       | ns                           |
| Causal I                     | 2.71           | 2.70       | .31       |            |            |           | 2.86            | 2.80       | .36       | ns                           |
| Causal II                    | 3.30           | 3.00       | .50       |            |            |           | 3.65            | 4.00       | .44       | ns                           |
| Seriousness                  | 2.80           | 2.75       | .58       |            |            |           | 3.10            | 3.00       | .53       | ns                           |
| Impact                       | 3.17           | 3.00       | .47       |            |            |           | 3.55            | 3.75       | .45       | Significant for Item 19 only |
| Congruence                   |                |            |           | .47        | .47        | .23       |                 |            |           |                              |
| Humanism                     |                |            |           |            |            |           | 4.09            | 4.08       | .62       |                              |
| Patient Satisfaction         |                |            |           |            |            |           | 3.63            | 3.87       | .50       |                              |

<sup>a</sup>Possible ranges were 1 to 4 for Causal Explanation: Total, I, and II, Seriousness, Impact, Patient Satisfaction; and 1 to 5 for Humanism.

<sup>b</sup>Based on using a Wilcoxon signed rank test (at the .0025 level) with each of the Hyperemesis Questionnaire items (see Table 4).

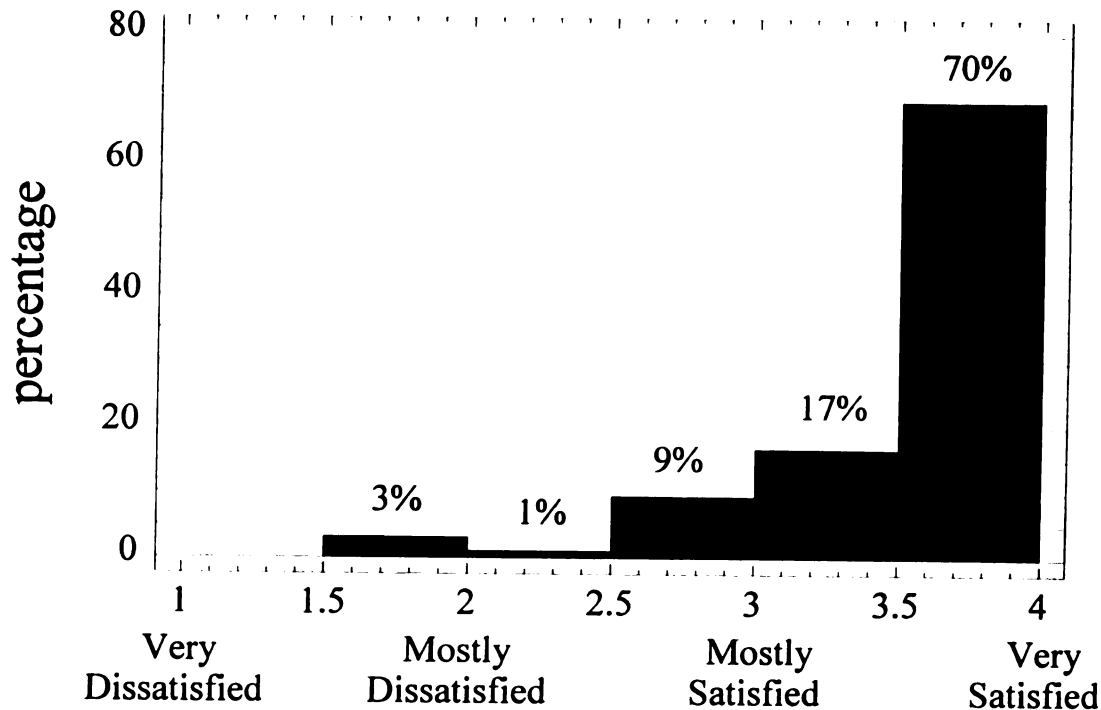


Figure 1. Histogram for Patient Satisfaction.

### Hypothesis 1

Patients who perceive that their doctors believed in a mostly biomedical causal explanation for HG will report greater satisfaction with the medical care received from their doctors. (Higher scores on measures of biomedical causal explanations will be positively associated with higher scores on reported patient satisfaction with care.)

Findings on the 4-point Causal Explanation scale (Total Causal) suggest that patients perceived their doctors slightly less than in agreement with the belief that HG is mostly caused by biomedical factors ( $M = 2.97$ ) (Table 2). Analysis of the two components that comprise the Total Causal scale showed that the mean score for patients' perceptions of doctors' beliefs for Causal Explanation I: General (2.71) fell



between *disagree* and *agree*, whereas mean doctor beliefs for Causal Explanation II: Personal Attribution (3.30) fell between *agree* and *strongly agree*. These findings suggest that patients perceived that their doctors had a tendency to believe that the etiology of HG for the general population is mostly caused by psychological factors, with a leaning toward the belief that the etiology of HG is mostly biologically based. However, patients perceived that their doctors maintained a stronger belief of a biomedical/physiological cause for a particular respondent's HG.

Spearman's rank correlation coefficient was calculated for Patient Satisfaction and Total Causal ( $r_s = .10$ ,  $p = .3080$ ) and was not statistically significant (Table 3). (The individual components Causal I [ $r_s = .17$ ,  $p = .1045$ ] and Causal II [ $r_s = .03$ ,  $p = .7554$ ] were also tested.) The null hypothesis was therefore not rejected. Higher scores on measures of biomedical causation were not associated with higher scores on reported satisfaction with care. However, due to the low reliability of Causal I: General (.3169), item-by-item Spearman rank correlation coefficients were calculated in order to test for significance. None of the five items comprising Causal I: General was statistically significant at the .01 alpha level.

Although the quantitative results demonstrated no significant relationship, the qualitative data tell a different story. The qualitative findings clearly point to a positive relationship between Causal Explanation and Patient Satisfaction. Qualitative comments suggest that for those participants who talked about their perceptions of their doctors' beliefs about the etiology of HG, the majority thought their doctors believed in a mostly biomedical etiology, were more satisfied when their doctors held this belief,

and (except for a few cases) were quite dissatisfied when their doctors suggested or implied that HG was caused by stress or psychological factors. For example, when asked what her doctor did or said that was helpful, one woman stated, "Just to know that he understood that it was just something biological or hormonal that happens to you, and it's not all in your head." Another respondent noted, "She explained that it was normal. Some people get it worse than other people," and yet another said:

Well, for one thing, he took it seriously. He didn't treat me like a hysterical female. I know, in talking to some of my friends, the other doctors are like, "Of course you're sick, you're pregnant." You know, pat you on the head and send you home. My doctor took me very seriously, was always available when I called. You know, he seemed to understand that this is a very real problem, and that I certainly had it.

Table 3

## Spearman Rank Correlation Coefficients With Patient Satisfaction

| Independent Variable            | $r_s$ | $p$ -value |
|---------------------------------|-------|------------|
| Causal Explanation: Total       | .10   | .3080      |
| Causal I: General               | .17   | .1045      |
| Causal II: Personal Attribution | .03   | .7554      |
| Seriousness                     | .13   | .2120      |
| Impact                          | .13   | .1941      |
| Congruence                      | -.20  | .0541      |
| Humanism                        | .60   | .0000*     |

Note.  $N = 96$  for all variables.

\* $p < .01$ .

Moreover, qualitative comments by study participants revealed higher reports of satisfaction when doctors attributed a mostly biomedical etiology for particular respondents' HG. Doctors' understanding that HG "was not all in my head" and that "I was really, really sick" were the predominant patterns. The vast majority of women voiced comments such as this respondent who said, "I felt that he understood that I was actually sick and it wasn't just in my head."

In addition, many women reported that they welcomed their doctors' exploring psychosocial factors that could contribute to the illness; they perceived this as a holistic approach, being treated as a whole person and not merely a medical diagnosis. However, they expressed feelings of disappointment, confusion, and anger in instances when their doctors continued to suspect psychological factors. Ongoing probing and questioning about psychological or stress-related issues by the doctors was interpreted by some women as suspicion of more than biological factors underlying the illness. For example:

I wasn't sure if he thought I was throwing up because of like bulimia or something. And I think he was questioning me for that and that made me feel bad because I didn't think I had anything like that. . . . He was questioning me like, "Have you ever had problems like this before? Is this something you have ever done before?" "How do you feel about your weight loss?" and stuff like that. So, I am sure it was probably for a good reason, I just felt weird. I heard the question like, am I having emotional problems? Because some of the women I met had hyperemesis at work [respondent is a home health care nurse]. One of them had gotten pregnant by rape and I kind of felt like, well, what are you questioning here? This was a planned pregnancy, it was a wanted pregnancy, everything about it was. . . . This was the first time I had ever been pregnant; [the questions made me feel] kind of dirty or like he thinks I am doing this on purpose.

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Another patient would have preferred that her doctor ask psychosocial-related questions rather than making a referral to the hospital social worker. She explained:

We have a relationship with him. Had he asked those questions I wouldn't have had a problem. But when the social worker asked the questions . . . I feel I wished he had communicated with me instead of having a social worker come talk to me and my husband. To me it was really irritating. I felt I had assured him and others that it was nothing personal; it was not stress-related. And I felt that he was questioning my sincerity.

### Hypothesis 2

Patients who perceive that their doctors believed that the HG was a serious medical condition will report greater satisfaction with the medical care received from their doctors. (Higher scores on measures of the degree of seriousness will be positively associated with higher scores on reported patient satisfaction with care.)

Patients' perceived mean score of 2.80 (Table 2) for doctors' beliefs on the 4-point Seriousness measure fell between *disagree* and *agree*. This finding suggests that patients perceived their doctors as believing that their particular HG illness was not a serious condition for mother and baby, although they perceived their doctors as leaning toward such a belief.

Spearman's rank correlation coefficient calculated between Patient Satisfaction and Seriousness ( $r_s = .13$ ,  $p = .2120$ ) was not statistically significant (Table 3). The null hypothesis was not rejected. That is, higher scores on Seriousness did not contribute to higher reported satisfaction scores.

Responses to the open-ended questions demonstrate that, of the respondents who talked about this issue, their views were varied regarding doctors' beliefs about seriousness. The women's comments can be categorized according to the four themes

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representing the Seriousness scale; "threat to patient" (Items 12-13), "threat to baby" (Items 14-15), "physician monitoring" (Item 16), and "intensity" (Item 11) are discussed qualitatively below. Qualitatively, patients' perceptions of doctors' beliefs about "physician monitoring" were clearly associated with patient satisfaction, whereas perceptions of doctors' beliefs that a patient's HG was a serious condition and posed a serious "threat to patient/baby" appeared to be unrelated to satisfaction. As will be discussed, with the exception of "physician monitoring," patients' perceptions regarding doctors' beliefs about Seriousness were reported by women within a context implied, but not clearly accounted for, by the quantitative scale. Overall, the qualitative data lend some support to the hypothesis.

"Threat to patient." Few comments were obtained from the open-ended questions that spoke to the issue of doctors' beliefs about the physical threat the illness posed to patients. Of the seven respondents who addressed this, three responses described doctors' voicing concern regarding their patients' health; two noted doctors' emphasizing to their patients that they "would be fine." Two additional women noted doctors' beliefs that their health and life were in serious jeopardy. One example, "I was high risk . . . for myself, my health." Another stated, "I was so weak I couldn't even pick up my hand. I thought I was going to die, literally die. And I think they [doctors] did, too, for a minute."

"Threat to baby." But for a few exceptions, the majority of respondents who talked about their perceptions of their doctors' beliefs about the threat to baby reported the doctors' belief that the "baby will be fine." Doctors informed patients that the baby

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"was getting what he needed" and "getting everything it needs from your reserves." Respondents perceived their doctors as validating these beliefs by confirming, via ultrasound, that the baby was alive and healthy.

"Physician monitoring." Physician monitoring was an indication to many respondents that their doctors believed HG was a serious condition requiring medical monitoring and intervention. Respondents elaborated on the variety of ways in which their doctors monitored their health as well as the baby's health status. For example, doctors encouraged patients to call with any problems, called the patient at home to inquire about her progress, conducted daily hospital rounds to "check on me," monitored the effects of the prescribed medicine, obtained frequent weight checks, monitored hydration status and instituted IVs if necessary, kept "really good stats on me" as an outpatient and inpatient, advised the patient to reduce activity in order to give the body rest, and increased the frequency of office visits. Also, admitting women to the hospital was especially viewed as an indication that the doctor believed the condition was serious. One woman reported with great emotion, "When he saw me he said, 'I don't even want you to go home. I want you to go straight to the hospital. I'm calling the hospital right now. You're supposed to go directly to the hospital.'"

"Intensity." The intensity of illness refers to the severity of its symptoms for the patient. With regard to the intensity, most respondents described their doctors' view of HG as a serious condition that required aggressive treatment and monitoring (e.g., "He took the disease very seriously," and "He let me know that it was serious"). Other doctors were described as viewing HG as more of a nuisance to be tolerated, or that

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would run its course. One respondent explained, "Basically I got the feeling right away that there wasn't anything you [doctor or patient] could do about it and make the best of it, and good luck." This woman did not consider her doctor's attitude as negative or minimizing her condition, but accepted her doctor's view that this was the nature of the illness. Still, others noted that their doctors did not fully appreciate the severity of symptoms as experienced by the patient. One woman, who reported overall satisfaction with her doctor because he "was encouraging, he just said to hang in there," went on to explain her disappointment in his attitude, "but I never really felt like he was taking it seriously . . . he just kind of blew it off like that was to be expected."

Thus, a distinction emerged within the "intensity" theme that clarified what was implied in the Seriousness hypotheses, yet was not borne out by the quantitative data. Women's comments pertaining to the Seriousness construct addressed their perceptions of their doctors' beliefs about *viewing HG as a serious illness* and *taking the illness seriously*. Respondents who viewed their doctors as believing their HG was a serious condition (Item 11) perceived their doctors as taking their symptoms seriously and subsequently reported satisfaction with care (which would yield a positive relationship between Seriousness and Satisfaction).

Others, however, reported satisfaction even though their doctors did not view HG as a serious condition because they perceived their doctors as taking them and their symptoms seriously. Thus, perceptions that doctors believed that a patient's HG was a serious illness were often sufficient (in the case of "physician monitoring") but not necessary (in the case of "threat to patient/baby") for enhanced patient satisfaction.

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This point is illustrated by one respondent who stated that "doctors need to tell patients that HG is not a serious disease, but they need to take it seriously."

Still, taking the illness seriously was clearly found to be related to patient satisfaction demonstrated by the qualitative comments. One dissatisfied respondent recalled:

I just didn't think that he took it seriously. When I was hospitalized I was passing out because I was throwing up so much, and it was like he still wasn't sure he wanted to put me in the hospital and my husband more or less demanded that I be put in the hospital. So I don't think he would have hospitalized me otherwise. . . . He was so quick all the time, and I just don't think it was sinking in. I didn't feel like he was concerned enough about it, where I was concerned about it because I couldn't function.

### Hypothesis 3

Patients who perceive that their doctors believed that the HG significantly impacted the patients' lives will report greater satisfaction with the medical care received from their doctors. (Higher scores on the measure of extent of impact on the patient's life will be positively associated with higher scores on reported patient satisfaction with care.)

On the 4-point Likert scale, patients perceived their doctors as *agreeing* ( $M = 3.17$ ) (Table 2) that the HG illness greatly interfered with their daily life and activities.

The Spearman rank correlation coefficient between Patient Satisfaction and Impact ( $r_s = .13$ ,  $p = .1941$ ) was not statistically significant (Table 3). The null hypothesis was not rejected. Higher scores on Impact did not contribute to higher scores on reported satisfaction with care.

Four themes comprised the Impact construct: occupational functioning, day-to-day functioning/self-care, social functioning, and family functioning. Despite lack of statistical significance, there is qualitative evidence pointing to a relationship between

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**Impact and Patient Satisfaction.** Although not many women discussed their perceptions of their doctors' beliefs about this issue, those who did thought that the doctors' feelings about Impact affected their feelings of satisfaction. The two primary themes that emerged from the qualitative data--which suggested that when doctors attend to issues surrounding women's personal and social lives, patients find this behavior helpful--were "slow the pace down" and "strain on family."

"Slow the pace down." One way that doctors attended to HG's impact on a woman's life was by writing notes to excuse her from paid employment outside of the home. Due to the unpredictable nature of the illness, some women required excuses periodically for full or partial days off. Other women were taken off work completely until the illness resolved to a more tolerable level. By using their "expert power" (Malterud, 1993), doctors validated the illness as "real," not only to the women but to those in the women's social world. Doctors' notes legitimized the sick role by sending a message to employers that the patient was ill, physically unable, and could not be expected to maintain work responsibilities.

I just was sick all the time, and he would give me notes for work so I could leave early. Sometimes if I would be sick and miss a day, he would give me a note saying I was really sick so I wouldn't get in trouble. And that helped. . . . Like working in a factory with all those men, they have no idea why I'm not coming to work every day. So he at least made it look legitimate, like I'm not just missing. . . . I wasn't just being lazy staying home.

Moreover, doctors' notes provided patients with the much-needed "permission" to "slow the pace down" and to obtain the necessary rest the body required in managing the symptoms of HG.

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I felt like I needed to slow down and be careful with each and every thing I did and ate and take it a little easier on myself. . . . At the time I was working hard, and the place I work is real hot. And he had me switch jobs and things like that . . . and I am kind of a perfectionist when it comes to my job. And I was constantly worried and trying to keep up with the work and stuff like that, and he basically told me to slow it down and remember that when you're pregnant you can't work at the same speed and do things like that you normally would. . . . In fact, he took me off work completely.

"Strain on family." In addition to slowing the pace down, respondents reported satisfaction when their doctors acknowledged how HG disrupted family life. Doctors demonstrated their understanding of family strain in two primary ways. Communication about or with family members was viewed as very helpful by respondents. Some doctors asked patients how their partners and/or children were coping. By merely "asking about," doctors were perceived as having an awareness of and concern for the patients' family life. Other physicians spoke directly with family members to offer verbal support as well as practical advice. One participant explained:

Unfortunately, my kids and I had to live with my parents for awhile, and my mother called him up all discouraged, you know, "What are we going to do?" And he took the time out to, you know, to talk to my mom and explain the whole thing and say, "Okay. These are some helpful hints for you and your family to get through this time." So, I mean, definitely he took the time to . . . also with my family too, I mean, not just with my husband but with my parents, and that really impressed me.

Second, doctors displayed their sensitivity to family functioning with attempts to medically manage the patients in their own homes, thereby avoiding hospitalization. Respondents reported that trying a variety of treatment interventions from home remedies to medications to arranging for home health care services (e.g., intravenous fluid hydration and visiting nurse) before resorting to hospitalization and/or multiple readmissions was very helpful. This was particularly important for women with young

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children. Home health care provided some semblance of normalcy within the home and possibly prevented children's being sent away week after week to live with other people.

Two women recalled:

Basically, it was very helpful for him to prescribe the medication so I could be home because I did have three other children. And he just kept an eye on the situation mainly and let me know he was there. . . . I think he was good in that sense, and supportive.

Just going back and forth to the hospital and my husband working and having a business, you know, that's difficult. You know, at least if you're at home he [husband] could hook me up there [home IV therapy]. Plus because we had the baby; Kevin was almost two I think. At least I was somewhat around.

#### Hypothesis 4

Patients who perceive that they and their doctors shared the same perceptions about the causal explanation, the degree of seriousness, and the extent of impact of HG on the patients' lives, as measured by the total congruence score, will report greater satisfaction with the medical care received from their doctors. (The lower the total congruence score, the greater the reported patient satisfaction with care.)

The mean Total Congruence score of .47 suggests nearly a one-half unit of differing beliefs on all HG scales (Total Causal, Seriousness, Impact) between respondents and their perceptions of their doctors (Table 2). Because a score of zero reflects perfect patient-doctor agreement, and a value of 3 is the greatest possible disagreement, this finding of .47 suggests relatively close agreement. The respondents perceived that they and their doctors were in agreement, for the most part, with regard to their beliefs about the causal explanation, the seriousness, and the impact of HG. Furthermore, the Wilcoxon signed rank test ( $p < .0025$ ) applied to each of the items showed that differences between doctor-patient beliefs were statistically significant for only 1 of the 20 items (Table 4).

Table 4

Wilcoxon Signed Rank Test of Doctor Versus Patient Average Item Differences of Patients' Beliefs and Their Perceptions of Their Doctors' Beliefs on the Hyperemesis Questionnaire

| Item                                                                           | Doctor-Patient Beliefs* ( <i>M</i> ) | <i>p</i> -Value |
|--------------------------------------------------------------------------------|--------------------------------------|-----------------|
| <b>Causal Explanation</b>                                                      |                                      |                 |
| <b><u>I: General</u></b>                                                       |                                      |                 |
| 1. In general, the cause of hyperemesis tends to be mostly biological/medical. | -.22                                 | .6964           |
| 2. In general, hyperemesis is mostly caused by stress.                         | -.20                                 | .6933           |
| 3. In general, the cause of hyperemesis tends to be mostly psychological.      | -.43                                 | .0037           |
| 4. In general, hyperemesis is mostly hereditary.                               | .04                                  | .9999           |
| 5. Hyperemesis is caused by both physical and psychological factors.           | .08                                  | .9999           |
| 6. (Item not used in analysis.)                                                |                                      |                 |
| <b><u>II: Personal Attribution</u></b>                                         |                                      |                 |
| 7. I got hyperemesis because I am a weak and sickly person.                    | -.32                                 | .3779           |
| 8. I could have prevented getting hyperemesis.                                 | -.34                                 | .2373           |
| 9. I got hyperemesis because I didn't cope well with my personal problems.     | -.30                                 | .3519           |
| 10. My hyperemesis was "all in my head."                                       | -.43                                 | .0409           |

Table 4--Continued

| Patient |  | Doctor |  |
|---------|--|--------|--|
|         |  |        |  |

Table 4--Continued

| Item                                                                          | Doctor-Patient Beliefs <sup>a</sup> ( <i>M</i> ) | <i>p</i> -Value |
|-------------------------------------------------------------------------------|--------------------------------------------------|-----------------|
| <b>Seriousness</b>                                                            |                                                  |                 |
| 11. My hyperemesis was a serious condition.                                   | -.40                                             | .0283           |
| 12. My own health was in danger from the hyperemesis.                         | -.18                                             | .9999           |
| 13. I could have died from hyperemesis.                                       | -.38                                             | .2805           |
| 14. My baby's health was in danger because I had hyperemesis.                 | -.38                                             | .0520           |
| 15. My baby could have died because I had hyperemesis.                        | -.35                                             | .6497           |
| 16. I needed close medical attention for my hyperemesis.                      | .00                                              | 1.0000          |
| <b>Impact</b>                                                                 |                                                  |                 |
| 17. My hyperemesis interfered with my job.                                    | -.39                                             | .0688           |
| 18. My hyperemesis interfered with my ability to perform my daily activities. | -.41                                             | .0594           |
| 19. I participated in fewer social activities because I had hyperemesis.      | -.46                                             | .0010*          |
| 20. Having hyperemesis created a strain on my family relationships.           | -.23                                             | .9999           |

<sup>a</sup>Negative values reflect higher patient belief scores on a 4-point Likert scale.

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It was predicted that a negative relationship would exist between Congruence and Patient Satisfaction such that the lower the total congruence score, the greater the reported satisfaction with care. Spearman's rank correlation coefficient (Table 3) yielded a negative correlation between Patient Satisfaction and Congruence ( $r_s = -.20$ ,  $p = .0541$ ), which was not statistically significant. Therefore, the null hypothesis was not rejected. Patients who perceived that they and their doctors shared beliefs on all three measures did not necessarily report greater satisfaction with the medical care received by their doctors.

The qualitative findings, however, lend support to the hypothesis that when patients and their doctors shared beliefs about various aspects of the illness experience (e.g., Causal Explanation, Seriousness, Impact), patients were more satisfied.

Because the Congruence hypothesis incorporates each of the three prior hypotheses, there is some overlap in the presentation of these data. Although this section will now include the quantitative findings for patients' beliefs compared to their perceptions of their doctors' beliefs, the primary focus of this section is to compare more specifically qualitative comments that illustrate the relationship between shared beliefs and patient satisfaction.

Total Causal. Total Causal scores on the 4-point Likert scale revealed that respondents' overall scores fell between *agree* and *strongly agree* that the etiology of HG is biomedical ( $M = 3.21$ ); mean doctor beliefs (2.97) fell between *disagree* and *agree* (Table 2). This difference was not found to be statistically significant based on the



Wilcoxon signed rank test applied to each item comprising Causal Explanation (Table 4).

With regard to Causal I, mean patient beliefs (2.86) and patients' perceptions of their doctors' beliefs (2.71) were quite similar. These scores fell between *disagree* and *agree*, reflecting a mostly psychological causal stance, yet with a leaning toward the belief that HG is mostly caused by biomedical factors for the general population. The Wilcoxon test applied to each of the items that make up the Causal I subscale showed no statistical difference between doctor and patient beliefs. However, Item 3 ("HG is mostly psychological.") showed a sample mean difference of -.43 between doctor-patient beliefs nearing statistical significance ( $p = .0037$ ), reflecting patients' stronger belief about a biomedical etiology for the general population of HG patients compared to perceptions of their doctors' beliefs.

Regarding Causal II, mean patient beliefs (3.65) denoted a value between *agree* and *strongly agree* that their particular illness was caused by biomedical as opposed to psychological factors. As perceived by patients, the mean score for doctor beliefs (3.30) showed somewhat less agreement about biomedical causation, although still between *agree* and *strongly agree*. The Wilcoxon test applied to each of the items that make up the Causal II subscale also showed no statistically significant difference between patients' beliefs and their perceptions of their doctors' beliefs.

The data showed that the majority of respondents were not as adamant about HG's being caused by mostly biomedical factors for the general population, but they strongly believed this was the case for their particular HG illness. Moreover, despite

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patients' reports of lower doctor belief raw scores on the overall Total Causal scale, as well as its two subscales, patients' beliefs and their perceptions of their doctors' beliefs were relatively congruent ( $M = .44$ ). Overall, raw scores suggest that respondents maintained a mostly biomedical etiologic belief compared to their perceptions of their doctors' beliefs, although these differences were not statistically significant for the individual items comprising the Causal Explanation scale.

Qualitatively, respondents tended to believe that HG was biomedical in origin, yet acknowledged the various roles stress played in their illness experience. They overwhelmingly voiced dissatisfaction when their doctors maintained a mostly psychological causal explanation compared to the respondents' biomedical belief. The qualitative data lend support to the hypothesis that perceived patient-doctor congruence about a biomedical causal etiology is an important determinant of patient satisfaction, particularly with regard to Causal II: Personal Attribution.

With regard to Causal I, qualitative statements provide support for the conclusion that respondents were less likely to presume that they knew the cause of HG for women in general. One respondent explained, "In my case I know it wasn't something psychological, so I don't want to say to don't have a social worker talk to the patients. Because I don't know what all could cause hyperemesis. I just know that in my case I think it was just something biological." Two respondents believed that it is likely that some women tend to be "complainers" and are "looking for sympathy." Thus, in their hesitancy to report a purely biomedical stance, respondents were in greater agreement with doctor beliefs that lean toward a mostly psychological stance.

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It is reasonable to deduce from the data that congruence between patients' perceptions of their own and their doctors' beliefs regarding the causal explanation of HG for the general population may not be an important determinant of patient satisfaction. Therefore, the finding of no statistically significant association between Causal I: General and Patient Satisfaction was substantiated by the qualitative data.

In contrast, the not statistically significant finding for Causal II: Personal Attribution was not supported by the qualitative findings. The majority of respondents attributed their HG to a physiological cause, with most believing HG is caused by hormonal changes of pregnancy and a few believing their HG was hereditary. An overwhelming number of participants adamantly voiced beliefs such that their HG "is real," "It wasn't in my mind," "I know it wasn't in my head," and "You don't make yourself throw up blood . . . who would want to do that?" Others explained that their HG occurred in the absence of any life stressors. One woman stated, "I didn't have no marital problems or no problems at work or whatever." Another concluded, "Believe me, when it goes away I feel just fine. . . . I mean I know it wasn't in my head because it goes away eventually. Nothing changed other than that I'm further along and that I know it's the hormones."

Furthermore, respondents reported satisfaction when they perceived their doctors' causal beliefs to be in keeping with their own. This was most apparent, however, when the shared belief was of a biomedical causation. In their own words:

He made me feel like I was doing my best and that it wasn't all psychological like some people thought it was, it was more physical.

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He understood when I told him how I felt, where other people didn't understand how I felt as though it was in my head where he knew it wasn't.

He told me that this is not something that I have caused by myself. This is something that my body just is not doing well with. Some people do fine and others don't.

Well, you know, a lot of people think it's all in your head. And then he . . . assured me that it wasn't all in my head.

Furthermore, patients expressed dissatisfaction with doctors who either overtly or covertly implied that their HG was caused by psychological factors, stress, or poor coping. Following are examples of two women who perceived incongruent causal explanations between themselves and their doctors.

He made me feel that there was really nothing wrong and that it was in my mind. And it was like I shouldn't call him or bother him for such a minor thing. [I didn't think it was in my mind] because I have always had a very strong stomach and I never threw up when I was younger and everything, and all of a sudden it was just like it was awful, I couldn't cook, I couldn't smell food, I couldn't smell my husband's after-shave lotion.

I remember my mom had talked to the doctor, and the doctor had said, "Oh, you know, a lot of it's just stress related. If you can just get the stress out of her life, she would do so much better." Well, that's easier said than done. You know, I mean, we all have stress in our lives, and that was really frustrating that my doctor was even thinking. . . . And, you know, I believe a lot of it is stress related, but there's more to it than just the stress. There's a physical part in there that you can't control no matter how stress-free your life is. You cannot control it. And I think that's where it was discouraging because he [doctor] knew about it. He had read studies, you know; but a lot of it all came back to everyone saying, "It's stress related, stress related. You need to do this. You need to do that." And it's like, "No, there's more to this. You know, I want to be up. I want to be taking care of my kids, but I can't. You know, I'm running to the bathroom every two seconds."

In addition, women reported being confused and angered by what they perceived as mixed messages. One participant commented that she was both reassured by her

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physician that the illness was not her fault and she did not cause the HG, and admonished by him such that if she would "try harder" she would be less sick.

Although respondents predominately believed in a biomedical cause for their HG, most acknowledged that "stress" played a role in their HG experience. The role of stress was described in three ways. First, of the 96 respondents, three reported that life stress was the primary cause of their HG. One attributed her HG to the recent death of her mother. Another believed that numerous life stressors occurring in a relatively short time contributed to her increased physical and psychological vulnerability. The third woman believed her HG was caused primarily by the stress of the physical, emotional, and verbal abuse by her husband.

Second, some respondents refuted the notion that stress was the direct cause of the HG, yet acknowledged that personal problems affected their illness and their ability to cope with the illness. Preexisting life stress was reported as a factor that made the symptoms worse, rather than causing the illness in the first place. One woman explained that her HG pregnancy was considered high-risk after years of infertility and two prior pregnancy losses. Another concurred that the stress of a subsequent pregnancy after experiencing a full-term stillborn affected her HG. She explained:

The main thing was that mine was a very unique situation--for me, anyway. So I think a lot of it was psychological in ways, and a lot of it was physical, and a lot of it was stress related. . . . I mean, I think the more stress you're under, the worse you feel, the more scared you are. But I still think most of it is physical.

In addition, others reported that relationship stress tended to exacerbate their symptoms. For example:

I went with my baby's dad for 20 years, and when I told him I was pregnant he married another girl. He would call me and we would argue, and then I would get sick. . . . I think I would have been sick anyway, but I don't think that helped matters at all.

I was in a bad relationship. My husband was very abusive. . . . And I have a feeling that the stress and anxiety, because he was a drinker and wouldn't come home for days at a time, of not knowing whether or not he was there or if I was going to have somebody in my house to help me with the older son and with the new baby. I think that played a lot. If I had a good mental outlook, it helped. I wouldn't get as sick as that. I mean, I'd still get sick, but I just wouldn't get *as* sick. . . . It [stress] affects it. I think it strongly affects the degree of the hyperemesis. I don't think that it caused it. I just think it didn't help.

Third, rather than life stress as a primary cause or a contributing factor of HG, most women noted the belief that the stress they experienced was not the cause of HG but was the result of the illness itself. That is, the problems associated with a pregnancy complication created stress. Statements such as "I wasn't stressed until I got sick" were expressed. Women described not only the emotional responses common to pregnancy complications, but also the vicious cycle that occurs wherein the physical symptoms and emotional response to the illness become intertwined. The severity and chronicity of the nausea and vomiting associated with HG created emotional responses such as fear and worry about oneself and the unborn baby, sadness and depression, and guilt regarding the effect on partner and children. These reactions, in turn, affected the illness, either by making the symptoms worse or negatively influencing the woman's ability to cope with the symptoms. One woman explained, "And, you know, some days I would just be feeling really, really bad [sad and anxious]. . . . When you feel really, really bad like that, that also affects your hyperemesis and, to me, your state of mind makes it worse."

In addition, the psychosocial toll that the illness placed on women and their families led many women to acknowledge the benefits of support groups, professional counseling, and programs that link women who have previously experienced HG with new patients. Some expressed frustration that their doctors did not offer referrals to these resources. An example of a satisfied patient is a woman who described how helpful it was for her doctor to share her belief that stress did not cause her HG but that HG created the stress. Her doctor proactively raised the issue of illness-related stressors and offered psychosocial referral information. In so doing, he validated the psychological and emotional impact of HG, yet he did not imply that HG was caused by an inability to cope with stress. She explained:

I remember he would be very supportive in the fact that it was mentally draining and that there was help available if I needed someone to talk to, help relieve some of the depression caused by hyperemesis. The hyperemesis was not caused by the depression, it was the reversal, it was caused the other way around. You know, you are very isolated and you are sick of being stuck with needles and missing your children and everything. So he was very supportive and understanding, and recognized things that even I was slow to bring up.

In sum, a lack of congruence in this area seemed to have implications far beyond a mere difference in belief about the origin of the illness. It appears to be related to issues surrounding the patient-doctor relationship, such as being believed and feeling understood. These findings will be presented under Hypothesis 5: Humanism.

**Seriousness.** The mean Congruence score for Seriousness was .47. Respondents' mean score of 3.10 (Table 2) on the 4-point Seriousness scale reflects a belief that they *agreed* that their illness was a serious condition for both themselves and their unborn babies that required close medical attention. The mean score for respondents'

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perceptions of doctors' beliefs was lower (2.80), reflecting a score between *disagree* and *agree* that the HG was a serious condition. The Wilcoxon test (Table 4) applied to each of the items that make up the Seriousness scale showed no statistically significant difference between patients' own and their perceptions of their doctors' beliefs.

However, qualitative comments supported the raw scores of different beliefs about the degree of seriousness. The overwhelming response from women was that they were "much sicker" than they ever expected to be and that the HG "lasted longer" than they expected it would. This finding corresponds to Item 11 ("My HG was a serious condition."), which yielded the largest mean difference (-.40) and lowest *p*-value (.0283), albeit not statistically significant, of all items comprising the Seriousness scale.

Furthermore, most women experienced much anxiety regarding the effect of HG on their babies.

The hyperemesis sometimes caused me to bleed. I would throw up so hard. So it, at that point, was jeopardizing for me to lose my baby because I was throwing up so hard.

I felt like I was going to miscarry.

I had a lot of concerns for the baby at that point, I think, because of all the testing we had to go through.

And the fear that, you know, with all the medicine, you know, if the child is really going to be okay; and if it's not, is it my fault for taking the medicine. I mean, that was definitely a fear, and I would worry every day. I would pray every day that the baby was going to be healthy.

Similarly, numerous women felt so ill that they thought they might die.

I thought I was going to die. I felt unlike I had ever felt before in pregnancy. I was convinced that I was going to die. Come to find out, I had no potassium left in my body, and it was making me kind of wiggled out, so . . . It was to the point of where my fingertips were flaking off, my lips were flaking off, my hair was

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falling out in bunches. I couldn't stand up; to vomit I would just lean over and vomit into a bucket because there was no way I could get up and go the bathroom. . . . You know, I was a gray, pasty mess.

I really just recall laying there thinking I was going to die. It was just awful being bedridden. I mean vomiting at one end and losing control of my bladder at the other . . . and then there's nothing coming up but the stomach bile. It was really hard.

In contrast, despite severe symptoms, one participant summarized why she did not believe she might have died from HG:

One of the questions you asked was whether I believed I could have died from hyperemesis. I answered no, but because I knew I was receiving proper medical care. I am certain that throughout history women and their babies with them did die from dehydration due to severe hyperemesis. With modern intravenous hydration this is no longer a threat in most places.

The qualitative data also lend support to the hypothesis that perceived patient-doctor congruence about Seriousness was an important determinant of patient satisfaction. Women voiced dissatisfaction in instances in which they believed the illness to be quite serious yet perceived their doctors did not share that belief. For example:

She didn't really say it was hyperemesis because I was able to keep a little bit of food down. She felt like it wasn't really that extreme. It wasn't until later, like now she does, like, sit and talk about that I had the hyperemesis. She made it sound like it was just the normal nausea and vomiting. You know, it wasn't.

Only one respondent, a home health care nurse who had treated cases of severe HG, reported that her doctor believed the HG to be more serious than she did. Incongruous beliefs in this case, however, led to satisfaction as the patient acknowledged needing the guidance of her doctor to prompt her to take HG more seriously. She explained:

He was sympathetic and also he took the disease very seriously. I think I kind of pooh-poohed it because I have known people that have had hyperemesis

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before; I have treated them as patients in home care. And so I was like "It was not so bad, I have only thrown up five times today." And he is like, "No, no, no. . . ." I was more brushing it off than he was, and he was the one who said, "You know, we have got to take this seriously." I needed help to reprioritize at that point, or I wasn't going to get any better.

In sum, the qualitative comments point to respondents' perceptions of greater seriousness compared to perceptions of their doctors' beliefs, despite the quantitative finding of no statistical significance. The qualitative data generally suggest that any incongruence between doctor and patient beliefs about Seriousness was the result of the belief that one's doctor was monitoring and treating the HG closely and, therefore, grave harm to self and baby would be avoided (see Hypothesis 2: Seriousness).

Overall, physicians' monitoring of, and medical treatment for, HG was interpreted by respondents as doctors' beliefs that HG was serious, and was associated with Patient Satisfaction. Furthermore, as previously discussed under Hypothesis 2: Seriousness, a pattern in the "intensity" theme regarding Seriousness was the distinction between viewing "HG as a serious illness" and "taking the HG seriously." Patient-doctor congruence about the latter also appears to be an important factor related to satisfaction that emerged from the women's narratives involving the topic of Seriousness and will be discussed further under Hypothesis 5: Humanism.

**Impact.** The mean congruence value for Impact was .44. Mean patient beliefs on the 4-point Impact scale (3.55) fell between *agree* and *strongly agree*, as did perceptions of their doctors' beliefs ( $M = 3.17$ ), that HG interfered with patients' daily lives (Table 2). The Wilcoxon test (Table 4) applied to each of the items that make up the Impact scale showed no statistically significant difference between doctor and

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patient beliefs for three of the four items. Item 19, addressing social functioning ("I participated in fewer social activities because I had HG."), showed a statistically significant average doctor-patient difference of  $-.46$  ( $p = .0010$ ). This reflects respondents' reports of greater impact on their social functioning compared to their perceptions of their doctors' beliefs.

As discussed under Hypothesis 3: Impact, few of the women's narratives addressed doctors' beliefs about Impact. As such, comments about any differences in doctor-patient beliefs specific to the social functioning item were not reported. Respondents talked primarily about their own experiences, such as "I couldn't go anywhere" and

I had two good weeks where I thought, "Oh, it stopped." Well, then all of a sudden I had a really bad week and was back on different medications. . . . So now I don't plan anything because if it happens to be a bad week, I have to cancel everything for that entire week and ship my kids off.

However, the qualitative data do lend support to the element of Impact within the Congruence hypothesis, such that when patients and doctors agreed about various aspects of Impact, patients reported greater satisfaction (e.g., "He cancelled my vacation, but it was necessary at that point; it was more helpful than hurtful."). In keeping with the discussion under Hypothesis 3: Impact, the most frequent qualitative responses illustrating shared beliefs about Impact were those related to the effect of HG on the family and paid employment. Respondents voiced satisfaction when their doctors agreed with them that prolonging hospitalization was not helpful for the patient or her family. One woman explained, "He told me that he knew that I wanted to be

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home and I would do better at home, that I didn't need to be in the hospital. So he was always working to get me out of the hospital."

Similarly, physicians' understanding about the need for work release was helpful to women. The importance of congruent beliefs between a respondent and her doctor about returning to work was expressed as follows:

He listens to everything I say and goes along with what I say. . . . [That was important] because I'm the only one that knows how I'm feeling, and I feel if he sent me back to work sooner than I wanted to go I would've went backwards. I think I would've gotten sick again all over. I think some doctors probably would have tried to send me back early, not understanding even though when I started to get well I would feel quite weak and tired all the time. It was quite difficult for me to even take a shower even though I wasn't throwing up any longer. He gave me a certain period of time to try to get well. And I don't know if every doctor would understand that.

Conversely, one respondent noted her frustration when she perceived her doctor as not understanding the financial necessity that she return to work. Although quite satisfied with her doctor overall and appreciative of his compassion, she believed that he did not grasp that she must work despite HG; she needed him to actively problem-solve with her ways in which she might manage the illness at work. She explained:

He did say things like "I want you to take off three months' work." You know, he said things that were impossible. That wasn't possible . . . because I knew I couldn't do it, and I needed to get ways to get through the day. Once he realized that, then, you know, he took it from there. . . . I couldn't just stay home every day.

### Hypothesis 5

Patients who perceive their doctors as more humanistic will report greater satisfaction with the medical care received from their doctors. (Higher scores on physician humanism will be positively associated with higher scores on reported patient satisfaction with care.)

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Values on the 5-point Humanism Scale ranged from 1 (*strongly disagree*) to 5 (*strongly agree*), with a total possible sum score of 120. Humanism scores that patients gave for physicians in this study ranged from the Likert values of 1.5 to 5, with a mean of 4.09 (Table 2) (actual values ranged from 36 to 120;  $M = 98$ ). This reflects that respondents agreed that their doctors generally demonstrated humanistic characteristics. The Spearman rank correlation coefficient was calculated, and due to the statistically significant positive relationship found between Patient Satisfaction and Humanism ( $r_s = .60$ ,  $p = .0000$ ), the null hypothesis was rejected.

The qualitative data lend substantial support to the quantitative findings. Moreover, comments by the study participants revealed particular aspects of physician humanism that were helpful and not helpful throughout the course of their illness that affected overall satisfaction. Because of the significant quantitative finding, the final coding frame for Humanism (Figure 2) is presented. Although the themes pertaining to each category of the class labeled Humanism are interrelated both within this class and between classes (Causal Explanation, Seriousness, and Impact), each category provides unique and meaningful information and will be presented individually.

Respects patient's viewpoint and considers her opinions when determining health care decisions. The main theme arising from the data in this category of physician humanism was "works as a team."

**"Works as a team":** Respondents voiced satisfaction when they perceived a collaborative relationship with their doctors. When the doctor and patient worked as a team, patients viewed themselves as active participants in the health care treatment

| Category <sup>a</sup>                                                                           | Theme                                                                                                   |
|-------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------|
| Respects Patient's Viewpoints and Considers Her Opinions When Determining Health Care Decisions | Works as a Team                                                                                         |
| Attends to the Psychological Well-Being of the Patient                                          | Physician Monitoring<br>Moral Support<br>Referral to Psychosocial Resources                             |
| Regards the Patient as a Unique Individual                                                      | Not Just a Number                                                                                       |
| Treats the Patient in the Context of Her Family and Social and Physical Environment             | Slow the Pace Down<br>Strain on Family                                                                  |
| Possesses Good Communication and Listening Skills                                               | Provides Information and Education<br>Taking Time to Listen<br>No Sugar Coating                         |
| Engenders Trust and Confidence                                                                  | Believes Patient's Story<br>Problem Solver/Action Oriented<br>Tries Hard/Sincere Effort<br>Always There |
| Demonstrates Warmth and Compassion                                                              | [See list of descriptive characteristics and behaviors.]                                                |
| Is Empathetic                                                                                   | Understanding the Illness Experience<br>Only My Doctor Really Understood                                |

Figure 2. Final Coding Frame. Class: Humanism.

<sup>a</sup>The eight components of physician behavior comprising the Humanism Scale (Hauck et al., 1990).



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decisions. Respondents explained the importance of being given choices regarding which treatment to pursue, and when to initiate or discontinue particular treatments. Their comments give life to the concept of patient-centered care advocated by Keller and Carroll (1994) and Seale and Pattison (1994). Following are the perspectives from three respondents:

I was appreciative that he gave me that choice instead of just saying we're going to do this whether you like it or not.

I felt like a partner in taking care of it [HG]. He respected my opinion of what was going on, too.

You don't need someone coming in and being rigid with you. You need people just trying to go with the rhythm with you, try and get on that wave.

In addition, when doctors included women's family members as part of the team, satisfaction was enhanced. One woman described her visit to the emergency room and the discussion among herself, her husband, and her doctor. She recalled:

[The doctor] came down and talked with both of us. And I remember him saying to my husband, "Do you think it's time for her to be here [hospitalized]?" And I remember my husband saying, "Yes." So it wasn't just even my opinion. It was almost a family decision or whatever.

Moreover, respondents voiced dissatisfaction when the doctors did not elicit their input regarding how to proceed in treating and/or managing the illness. For example:

Well, he talked to me like I was a child; and he was going to do something good, but not totally explain it first. . . . It made me angry. It was hard to deal with when you are sick; and to have someone come in and tell you how it was going to be was not helpful.

Attends to the psychological well-being of the patient. The data showed three primary ways that doctors attended to the psychological well-being of their patients.

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These were "physician monitoring," "moral support," and "referral to psychosocial resources."

**"Physician monitoring":** The first and foremost concern for the participants in this study was the health of their unborn babies, followed closely by their concern for their own health. As discussed earlier in this chapter, "physician monitoring" was a theme described by respondents as an indication that the doctor believed the condition was serious enough to require close observation. It also served another purpose. "Physician monitoring" addressed women's psychological fears and worries about themselves and their babies. Women reported satisfaction when they received verbal reassurance based on their doctors' experience in treating HG, as well as reassurance from objective medical test results confirming that the baby was developing properly.

For example:

I always felt better because he always reassured me that everything was okay with the baby, even if I was throwing up, and that I was fine; that the baby was going to be fine even if I was sick. He always reassured me that everything . . . every time he measured me or heard the heartbeat or whatever, everything was fine.

Moreover, this reassurance was necessary throughout the pregnancy, even after the HG had resolved. Some women worried throughout their pregnancies that the HG might have impaired their babies' growth and development.

Throughout the pregnancy he was reassuring, telling me it looks like her birth weight is going to be good and like that . . . because that was a concern of ours, that because I was so sick for three months that she wasn't going to develop at the right rate.

Additionally, reassurance that the "baby is all right" was not sufficient for most respondents. After learning of the potential serious risks to the baby some time after

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the birth of her healthy baby, one respondent voiced her anger that her doctor had never informed her of the danger; had he informed her, she believed she might have tried harder to eat more. Similarly, others reported satisfaction when their doctors provided straightforward information when the babies were possibly in jeopardy. In one respondent's words:

She always laid things on the line if the baby was in trouble or if there was anything going on. She was always totally honest with that, and that I appreciated because with one baby we had a blood clot behind the baby. Well, I had hyperemesis and there were other things going on. So I always appreciated knowing what I was up against.

In contrast, only one respondent reported that although she understood it was her doctor's "job," she found it more stressful to be informed of the potential risks to the baby.

Respondents also benefited from reassurance that their own physical health was not in jeopardy and that there was nothing else wrong with them. Some women reported being so ill that they feared an additional, more severe illness was possibly underlying the HG.

**"Moral support":** Second, doctors attended to the psychological needs of these women by providing moral support, words of encouragement and hope that the patients could and would make it through the illness. Numerous women discussed how helpful it was to be continuously reminded and reassured that "the end is in sight," "[I] could get through it," and "it would get better." One woman's response summarizes this category. She reported, "[I felt] like I had hope--that I was going to be all right. He didn't know

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when, but he just gave me reassurance it wouldn't last forever. The hell I was going through would stop."

**"Referral to psychosocial resources":** Last, most women reported being appreciative that their doctors referred them to psychosocial counseling and/or local support programs for HG. One woman was grateful that her doctor referred her to the support program that linked her with another woman who had had HG in the past. She stated:

I think that the support group like the Parent to Parent is something wonderful to offer people with hyperemesis because you feel awfully alone. When I had my first experience, I never knew anyone before who had it. I thought I was some freak. You know, what was wrong with me that I couldn't handle a simple little pregnancy? I think that doctors need to know that these programs are there and tell their patients about them, give them that option.

Women who did not receive information and referrals about these resources recommended that this be done for future patients. For example:

I would definitely say the main suggestion would be, from what I've heard from girls that have been in the hospital for what I had, . . . I think that maybe a counselor or a social worker or something can be provided for the girl at the hospital just to talk out some of those things while she is there.

I remember thinking I wish there was a support group because it's something that people don't understand unless you have been through it.

Regards the patient as a unique individual. The data demonstrated that the women in this study reported satisfaction when their doctors treated them as a unique individual and "not just a number."

**"Not just a number":** The theme of "not just a number" emerged, which exemplified satisfied respondents' perceptions of the personal treatment they received



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from their doctors. Moreover, spending time with a patient and not rushing her was a behavioral indication that the patient was not just another case. For example:

I wasn't a number. I wasn't just one of the many faces.

He always made me feel like I wasn't a number after speaking to him. He would never interrupt me, and he would never make me feel like "Oh, I gotta see another patient," and that was really important to me.

He didn't rush me. I didn't feel like a number.

You would go in and you'd wait and wait and wait for him, but he always made you feel like you were just there by yourself, [like] he didn't have so many other people.

The doctor that we have for this pregnancy treats you like an individual, like you count, and I think that's really important.

Conversely, feeling rushed by the doctor was perceived as a lack of individual attention. One woman recalled, "I felt unimportant because he had a really rushed bedside manner. It is like he was in and out within minutes."

Treats the patient in the context of her family and social and physical environment. Qualitative data relevant to this category describing the themes "slow the pace down" and "strain on family" were addressed under Hypothesis 3: Impact and Hypothesis 4: Congruence, Impact.

Possesses good communication and listening skills. Themes regarding both information content and the process of communicating that information were cited by study participants. These included "provides information and education," "taking time to listen," and "no sugar coating."

**"Provides information and education":** The data showed that respondents were satisfied when they received information and education about HG. "Explaining

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things" and "answering questions" thoroughly were the forms of good communication most frequently cited by study participants. Moreover, proactive communication on the part of the doctors was most appreciated. That is, patients were pleased when their doctors anticipated their questions and concerns because they worried that they did not always know exactly what questions to ask. As one dissatisfied woman stated:

He didn't give me any information except what I asked for. So if he had been a little more open or a little more informative, then I wouldn't have worried about it. I mean, it was more like I had to think about it and worry about it all night and then ask him the next day as it came up. [If some things had been explained] before it came up, I wouldn't have worried about it all day, . . . and especially because not only was it my first pregnancy, it was basically my family's first pregnancy. So it was totally, you know, I couldn't go to anybody else either . . . so it was really confusing for me.

In addition to oral education, respondents desired more written literature and brochures, as well as videotaped information.

Satisfaction was related to specific content areas of HG. These topics were (a) information and education regarding the nature of the illness (e.g., illness course, severity, duration, incidence); (b) treatment interventions; (c) potential physical effects on mother/baby; (d) medical research to date; (e) other case examples; and (f) modifications in lifestyle that may facilitate illness management and recovery. A satisfied respondent described her experience:

He really helped by showing me what I could and couldn't do, how to eat, when to eat, and what to eat. He gave me a diet which I would never have thought of. I mean, I even could eat chocolate, but he said you've got to eat it at certain times. I don't think I would have been able to have made it [without that diet]. I would have been in the hospital more. It helped keep me out of the hospital to the point where I could care for myself at home. . . . This doctor took the time to explain to me exactly why this [HG] was like this to the best of his knowledge, and he showed me what I could and couldn't do and how to help. He told me the less activity I did would help because it would stop the irritation. [He helped

me] to deal with it, to cope with it, and how to keep going on with my everyday life because I had another child already at home. So he was helping me to be able to cope with everyday life.

Still another respondent thought that delayed information regarding the diagnosis and behavioral-management strategies increased the severity of her symptoms such that hospitalization was required. She stated:

Not until I was in the hospital did I ever hear that word [HG]. . . . So, I guess I was misinformed and felt I didn't know what to do to try to have prevented it from going to that extreme.

Moreover, respondents noted the importance of their doctors' telling them about other case examples of HG. Verbal validation of the illness and the patients' experience exemplified the type of psychosocial content that women found extremely helpful. For example:

When you see people around you who are pregnant and don't even slow down, and you're sick and throwing up every day, it's hard. At least then you know other people have had it and it's not all in your head because I'd worry thinking maybe I am just overwhelmed, and this is all psychological. But then at least the doctor would help me think, "No, you're not going crazy. It happens."

He told me that it was common. I guess that's what didn't make it feel so bad. He told me that it was common, that it happened to a lot of people. It didn't make me think I was the only one.

Furthermore, doctors' communication skill was an indication to patients of physicians' knowledge about HG. One respondent reported, "I felt better because my doctor knew all about it and so he understood." Although physicians' knowledge and expertise was reassuring, when doctors were open and honest about their lack of knowledge and were willing to seek out the answers, patients also voiced satisfaction.

For example:

If he didn't know the answer to something he would tell me he was not sure and he would go find out.

So I don't want doctors to come off being show-offs thinking they know exactly what hyperemesis is because they don't. And women just need to know that their doctor is going to be there to support them and help them through it.

**"Taking time to listen":** As important as the content was, the manner in which information was imparted was also related to satisfaction. "Taking the time" to "listen" to the patient's account of her situation in a supportive and empathetic manner were two functions deemed imperative, not only as humanistic qualities, but also to the health and well-being of mother/baby. One woman's comments illustrate this point. In her words:

I think it's important, no matter what kind of doctor it is, because even though they have the knowledge and the expertise in that particular field, nobody knows their body like the patient does. Nobody knows what they are feeling better than the patient does, and if doctors don't listen, I don't think they can properly meet the needs of their patients.

**"No sugar coating":** In addition to feeling listened to, respondents were clearly satisfied when doctors "laid things on the line," were "always honest," "didn't lie to me," and "didn't sugar coat it." And although troubling information about risks to the baby, in particular, was difficult to hear, most voiced the importance of accurate, honest information to their coping as well as to their trust and respect for their doctors.

Engenders trust and confidence. Although each of the eight Humanism categories contributed to patients' trust and confidence in their physicians, four particular themes emerged as unique to this category. They are "believes patient's story," "problem solver/action oriented," "tries hard/sincere effort," and "always there."

**"Believes patient's story":** Women's confusion surrounding the mysterious and unfamiliar physical symptoms of HG dissipated when they and their doctors mutually constructed a definition of the experience. Patients were comforted that their doctors had knowledge of the illness and felt validated by their doctors that this "was real." Before being diagnosed with HG and with no previous knowledge of the term, many respondents explained their inner sense that "something was not right." Even women pregnant for the first time and uncertain about what nausea and vomiting of pregnancy (NVP) should actually feel like reported that they "knew deep down" that what they were experiencing went beyond NVP. Thus, giving a name to their somatic experience definitely provided relief and comfort for the women in this study. This is in keeping with Brody's (1987) account of the comforting quality of making the diagnosis. He stated:

One aspect of the stories mutually constructed by physician and patient that explains their comforting quality is that they fit Kermode's (1967) definition of a "concord fiction." The sick or anguished patient experiences himself as being in a terrifying and mysterious "middle" that seems to make no sense. The physician comforts and makes the experience understandable and controllable by supplying an account of a beginning and an end that make the "middle" comprehensible in relation to them. This further reinforces the importance of providing an account of disease causation and disease prognosis in all encounters with patients (Kleinman, Eisenberg, & Good, 1978). (p. 9)

Furthermore, the data suggested that before doctors named the illness as HG, they first had to believe the patient's story. Based on the qualitative comments, patients' satisfaction with their doctors in the treatment of HG was strongly associated with women's perceptions that their doctors believed their accounts of their symptoms.

By believing patients, doctors took the illness seriously, thereby creating an atmosphere of trust and respect. For example:

The most helpful thing was just, in the beginning, just acknowledging that I was sick enough to be admitted to the hospital, that I couldn't go on anymore at home. That this was really happening, and I couldn't control it. And that I wasn't making it up. I knew I wasn't, but [it helped] that someone believed me.

He took me seriously when I had a complaint. He never gave me the brush-off. He never once hinted that it was psychological, as a lot of people can do when they don't understand it. . . . He really seemed to grasp how miserable it was.

I always felt okay after seeing him. . . . He did take me seriously, and I didn't feel that he felt I was crazy for my symptoms or anything.

In addition, a pattern emerged from the data between doctors' believing the patient's story and their giving name to the illness. A few of the women who reported having experienced previous HG pregnancies (those that were diagnosed and not diagnosed) described their doctors as being more responsive with the subsequent HG pregnancies. They discussed how they did not need to "prove themselves" quite as hard as they did with the first pregnancy, in which the doctors had treated their physical signs and symptoms as more suspect. One respondent recollected:

The third time he was a lot more compassionate. He was so different the first time around because I think they [doctors] just think the first time around, "Oh, she just doesn't know what it's like to have morning sickness." And I just assumed that that's what it was supposed to be like. So I went in there, and I had lost 20 pounds. He said, "Yes, definitely, something's wrong with you," but they didn't take it seriously until [I had lost so much weight]. He was really young the first time around. I know he didn't probably [act that way] deliberately.

Another related pattern was found such that even though women had an inner sense that something was not right, many described a tendency to "second-guess" themselves. Without a clear diagnosis explaining their symptoms, and even after the



diagnosis of HG had been made, some women questioned themselves with thoughts such as, "Maybe it is psychological?" Further, although women were more likely to doubt themselves in their first pregnancy experiences, as demonstrated by the woman just described, some noted self-doubt in subsequent HG pregnancies as well. Second-guessing oneself particularly occurred in the context of receiving "all in your head" messages from other health care professionals, family, and friends (see Other Relevant Findings).

One woman discussed how helpful it was for her doctor to provide ongoing reassurance that she was not to blame for getting HG, and that her doctor understood just how "mentally draining" the HG was for her. She stated:

You, yourself, start to believe it is all in your head. Enough people tell you it is all in your head, you almost start to believe it yourself, and that makes it even worse because you don't choose to throw up 25 times a day. You don't choose not to have a social life, to get up and share in regular things like just going outside and smelling fresh air. You don't choose to be on your back for that long and just watch TV, especially if you are how I am, I am always on the go. And not being at work and being separated from people and being isolated was an awful thing for me.

Another explained:

[It was helpful] for the doctor to say it's not in your head. . . . As a nurse, too, I knew it wasn't in the head because that was part of my job to tell people that. But it's just nice to have that reaffirmation. When you're real miserable sometimes your focus can be kind of blurred because you're so miserable, and you think, "What's wrong with me? Why can't I just get up and feel better?" So it helps to have that understanding.

Moreover, the data suggested that some women may wait longer than necessary to contact their doctors to ensure that they will be taken seriously. For example, one patient who reported much satisfaction with her doctor recalled her strategy, stating,

"I wasn't one to call every day either. I kind of just waited until it got so severe that he knew it was that bad." Thus, even in cases in which the doctor was extremely understanding and reassuring that HG was not psychological (and in this example the doctor had been through two previous HG pregnancies with this patient), there were enough self-doubting internal and judgmental external messages to this effect, prompting women to strategize ways to protect themselves psychologically.

Some women delayed contacting their physicians because of previous experiences with doctors who took little action and minimized the symptoms. For example:

I suffered a long time [with this pregnancy] before I was willing to admit that I was beaten. Because with my first two, nothing was really done about the hyperemesis. I remember my doctor, who was a woman, at the time saying, "Be glad you can keep down the chicken noodle soup because otherwise you would be in the hospital." So that was the attitude she had. I would just on my own do what I could to keep from being hospitalized. So when I went into my third pregnancy I did the same thing. I did what I could or what I thought I could to keep from having to ask the doctor about it or having to be hospitalized. And then when that didn't work I felt like I was the failure, that I didn't do enough. That is why I am grateful that I had a new doctor [this time].

Thus, some women employed unique strategies for interacting with their physicians and tried to manage their symptoms independently when they perceived it was pointless to contact their doctors, or when they sought to avoid physician rejection (e.g., perceived messages from the physician that the patient is overreacting and not *really* sick). The pattern of "second guessing" oneself, then, further establishes the importance of doctors' providing continual education and reassurance because some patients may blame themselves either for causing HG or for their supposed slow recovery, and may, themselves, delay treatment.

To summarize, the findings suggest that feeling believed by one's own doctor was not only important to these women in terms of feeling validated (e.g., I'm not crazy; this is a real illness), but was imperative to their receiving the much-needed medical treatment. That is, when doctors believed patients' stories, they made the diagnosis of HG and subsequently took action.

**"Problem solver/action oriented":** Patients' satisfaction was enhanced when doctors were "action oriented" and "problem solvers." One woman commented that her physician "believed me and took measures to help me." Actions perceived as helpful ranged from verbal instruction and recommendations, to explanations regarding why taking no action at a particular point was an appropriate intervention, to the aggressive treatment of the illness with home health care, hospitalization, medication, and IV fluid therapy.

In particular, as mentioned before, the first action necessary was that of making the diagnosis. Dissatisfaction ensued when patients thought their symptoms were minimized and not taken seriously. And although some noted that this occurred after the diagnosis had been made, the primary pattern found in these data was the perception that the diagnosis could, and should, have been made sooner than it was, that doctors often downplayed the symptoms for several weeks before making the diagnosis. Although some acknowledged the physician's predicament of watching and waiting to determine whether a woman had NVP or its more severe form, HG, most voiced frustration regarding how long it took their doctors to confirm the diagnosis of HG.

For example, one patient noted her frustration during the first four weeks of her illness before the diagnosis was made. She reported that she got the impression from her doctor via the office staff that "You're pregnant, and this is a part of being pregnant. Some women get sick, and you need to get up, and you need to deal with it." However, she noted that once her doctor made the diagnosis, it was treated seriously. She stated, "Once she diagnosed it, she was so wonderful. And . . . after I came out of the hospital and had to go for my first checkup, you know, she treated it like it was so serious." She went on to describe her confusion resulting from the mixed messages she received regarding her symptoms: "And I was like, kind of like, dumbfounded because she's like, 'You need to call as soon as you feel like that,' and I'm like, 'I called every day. I called three times a week. I'm in here getting my ketones checked. What do you mean? What more can I do?'" The respondent went on to question the possibility that her doctor might not have received accurate information from the office staff. She argued, however, "It's her job to be informed, and I'm sure it's all written down that I've called and that I've been in there because they weighed me every time and recorded it."

Other examples from the women's narratives included:

They need to take it more seriously and not to wait as long to see if it goes away.

I didn't really understand what hyperemesis was until after I was sick. I thought I just had really bad morning sickness. I think the only thing that bothered me was it took a long time for them to diagnose it.

Keep a closer tab on them [patients] in the beginning so they don't have to suffer for weeks before they come in and tell you [doctor] they can't take it anymore.

I guess in some circumstances maybe don't wait so long for the IV therapy. . . . I think they held out a little too long before I got serious treatment that I am sure I needed a little sooner.

Furthermore, some noted the possibility that there may be women who "cry wolf" and are not "really sick," although the respondents in this study were adamant that most women, including themselves, do not cry wolf. One woman explained:

I just think they [doctor's office] need to not schedule an appointment three weeks from now when they [patients] are that sick. Because you shouldn't have to go through seven weeks of pure hell to have something done. I think they [patients] also need to have a personal [relationship with the doctor]. You know, you probably get eccentrics that think that they're dying, too, so it's probably hard for them [doctors] to judge. It's just like, you know, I lost 20 pounds in two weeks. That is a sure sign right there.

Finally, one patient was upset regarding what she perceived to be delayed diagnosis and treatment and changed doctors in the midst of her HG pregnancy. She recalled:

Well, it started around six weeks or so, and I would go in and I would say, "You know, I don't feel good." And he'd say, "Well, it's morning sickness," and he'd tell me various things to try. And I tried everything, and nothing was working. And I felt like too much time elapsed where nothing seriously was done about it. That's why we ended up after this incident switching doctors, because we weren't happy with the expediency, I guess you could say, of realizing that I did have a problem and I needed help with it.

Next, "flexibility" emerged as a pattern within the "problem solver/action oriented" theme. Flexibility on the part of the doctor was seen as contributing to patients' satisfaction. When doctors were flexible in "trying different things," patients perceived them as less rigid and willing to individualize their care.

In contrast, a few patients found a flexible treatment approach to be anxiety provoking. They described feeling discouraged that nothing was working and were frustrated with the "guesswork" involved in treating HG. One woman described feeling

"like a guinea pig because they just kept trying all these things and nothing seemed to be working." Another explained:

They played around with my medication a lot which, I think when you have hyperemesis every day, it's three years long. And every night is endless. And when they want you to give it a shot for a week or so, that's an eternity. They put me on Compazine, and it wasn't doing anything. "Well, give it a chance, give it three more days, give it four more days, let it get in your system." Well, those four days, that's like saying, "Take this for four more months and we'll see how you feel." That was real hard on me when they played around. None of the anti-nausea medications ever did work. That wasn't helpful. I think that when I say this isn't working, that I feel no difference, they should have thought, right then and there, "Gee, it is her body, she should know." So that is one thing that I wasn't real thrilled with.

**"Tries hard/sincere effort":** Respondents placed additional importance on the physician behaviors of "taking action" and "active problem solving." Taking action and being flexible in trying a variety of treatment interventions was also an indication to patients that the doctors were trying everything they could possibly do to help the mother-baby dyads. A sincere effort on the part of the doctor was an important factor contributing to Patient Satisfaction.

He tried his darndest to help me out. . . . You know, he's just a doctor. So he tried the best he could . . . he tried his best to make me feel better.

He was willing to fight as hard as I was, if not more sometimes. . . . And he was very aggressive in fighting it, in finding different ways to find out how individually I could deal with it.

He tried various things with the various anti-nausea drugs and had pretty much exhausted the list of what they typically prescribe. And then he did some additional research on his own and talked to another doctor and came up with a kind of a last resort anti-nausea, which was something that he uses for chemo patients. It's called Zofran. I guess I kind of felt like he went an extra step to try something else to alleviate the vomiting.

Moreover, when patients perceived their doctors as trying hard, greater confidence was instilled in the patient-doctor relationship. One respondent described the lengths her physician had gone to, even buying special equipment for her to try:

I sincerely feel he tried everything . . . like putting a sea band on my hand because he said people who are on ships also get nauseated. He, himself, went and bought the sea bands from somewhere. I think in my heart I knew he did everything he possibly knew to control it. [It was helpful to me that he tried everything because] I wouldn't have felt confident in him if I didn't feel that he attempted everything.

**"Always there":** "Believing the patient's story," "taking action," and "trying hard" were themes of physician behavior that were reported as contributing to patient satisfaction. A final theme, "always there," was reported by the study participants as an important humanistic quality for physicians. This theme, like the more commonly used phrase "being there," was discussed in two ways. First, it was described in terms of the practical issues of physician availability and accessibility. For example:

If I called today and I didn't think I was feeling too good or I didn't think that the baby was moving as much as he should be, he would get me into the office the same day.

He was available to talk to me. He would phone to see how I was doing.

When I was at home, she called me to make sure I was okay before the weekend. Any time I called, she took my phone calls. If I was really upset when she would call, she would tell me to go to the hospital or to come to her office so she could do a urine [test]. She just was there whenever.

When I did call him like on the pager or whatever after hours, he took interest in what was going on. He didn't just slough me off or anything.

She did encourage me to call any day, any time of day, day or night. She was there, or if she knew she wasn't going to be there, she gave me the name of another physician that would be there for me to call.

I could call at any time, day or night. He was very accessible and tried to do anything he could to try to help me get through it.

Second, "always there" was discussed in terms of the more abstract level of perceived emotional support. For example:

He was always there when I needed him all those different times.

He came in every single day, and some days there was really nothing he could do for me; but I still appreciated the support, I guess, of knowing he was there.

Demonstrates warmth and compassion. The data suggest a number of physician qualities that were helpful to respondents throughout their illness experience. The demonstration of warmth and compassion by doctors can be characterized by personality attributes as well as verbal, nonverbal, and behavioral interpersonal skills. Furthermore, these physician attributes were frequently described by patients as skills necessary to practice good medicine. They were not viewed by respondents as optional skills, secondary to technical skill. They often were defined as traits and behaviors that should be expected of doctors, just as medical knowledge and technical expertise are presumed.

A thorough account of this category goes beyond the scope of this dissertation. As such, the most frequently noted descriptors and salient comments by respondents related to patient satisfaction are listed below:

Nice  
Warm  
Easy going  
Good sense of humor  
Caring  
Reassuring  
Sympathetic  
Compassionate



Encouraging  
 Concerned  
 Genuine concern  
 Hopeful  
 Caring  
 Comforting  
 Trusted  
 Professional  
 Humor  
 Helpful  
 Supportive  
 Calming  
 Patient  
 Kind  
 Cheery  
 Positive  
 Optimistic  
 Understanding  
 Excited about baby  
 Wonderful bedside manner  
 He'd bend down and ask me how am I doing.  
 She hugged me every time she saw me in the hospital.  
 He prayed with me.  
 Touch on the shoulder  
 He was just a good support person, you know, almost a friend, somebody that  
     you would meet and consider a friend rather than a doctor.  
 Even though I was feeling lousy at the beginning [of the office visit], he still  
     would make me laugh when I came in there.  
 He would joke.  
 He would try to cheer me up.

The only two specific negative descriptors were "rude" and "short/abrupt." In addition, other comments described opposite qualities such as "awful bedside manner," and "He didn't really care to understand."

Is empathetic. Empathy involves the understanding of a person's feelings and the communication of that understanding (Rogers, 1957). Two primary themes pointed to the category of the empathetic quality of physician humanism. They are "understanding the illness experience" and "only my doctor really understood."

**"Understanding the illness experience":** Respondents noted satisfaction when their doctors demonstrated an understanding of both the physical and emotional aspects of the illness experience. As mentioned under Hypothesis I: Causal Explanation, believing that HG "was not all in my head" and that "I was really, really sick" were the predominant patterns contributing to patient satisfaction.

Similarly, doctors' understanding of the complex emotional and psychological aspects of the illness was seen as very helpful by the study participants. For example, one woman thought her doctor fully understood her desire to avoid hospitalization; however, she appreciated his gentle explanation regarding the necessity of such.

In addition, a few respondents found comfort in the fact that their female physicians had personally experienced HG. One reported:

First of all, she always explained things, and she never implied that there was any psychological component. She knew. She had experienced it, so she knew how it felt. She just kind of freed me to accept it as a medical condition. And I could talk to her about it, and nothing seemed bad or seemed weird because she had been there. And I knew she really did care. I mean, when she would come in, she would hold my hand and rub my hand and just kind of really be present to me, and you really need that because you're so isolated.

Others explained that although their doctors "might not have understood everything" and "there was no way in hell he understood exactly what I was going through . . . you know, he's a man," they perceived physician empathy when the doctor "tried" to understand and "believed I was going through something." Furthermore, the interrelated linkages of the themes and patterns within the Humanism category as they relate to satisfaction is apparent. One woman explained that trying to understand and

believing patients' stories enhances patients' ability to trust their doctors. She explained:

If you feel comfortable in knowing that your doctor believes in you, not understands, but tries to understand what you're going through, that is going to relax you a little more. You are going to relax and put yourself more in their hands and let them treat you. If you think someone's not quite buying what you're saying, you know, you get a little up in arms. I think that's a stress reliever right there. And, everything else in your life is chaotic; you need the soothingness of someone understanding.

Patient satisfaction was negatively related to Humanism when patients perceived their doctors as lacking understanding of the physical and emotional aspects of HG. They noted displeasure when they perceived their doctors as not comprehending the extent of the vomiting associated with HG and the subsequent physical and emotional difficulty of adhering to dietary instructions.

He would always send me home telling me I have to eat more. "You have to drink more liquids. You have to eat more." And it kind of made me angry because when you have hyperemesis, no matter how much you try to eat and drink more, it doesn't help. You finally get to the point where you just are so sick of putting something down there when you just know it's going to come back. That was very discouraging because he really did not understand what it felt like.

Sometimes I would feel like [my doctor thought] I was overly concerned and just being ridiculous, like I was worrying too much or that sort of thing. I guess I felt like she wasn't there with me all the time. She didn't see how it was affecting me every day and all the time. So she didn't really understand that it was, you know. . . . The fact that I could keep half a piece of bread down for one day wasn't reassuring to me.

**"Only my doctor really understood":** A theme that was unanticipated emerged within the category of physician empathy. Of the women who discussed physician empathy, some noted that of all the people in their social support network, it was their physicians who understood their situation the most. In their physicians'

presence, they felt affirmed, validated, and understood. They attributed this quality as something inherent in the professional role of the physician (e.g., Doctors "deal with patients and see how patients really feel."), and as a result of the doctor's personality (e.g., "He's a good person."). Examples of other narratives included:

I felt like someone was with me. He was one of the very few people that when he left the room I didn't feel like I was stupid anymore or I was crazy. He actually listened.

I mean I always felt like nobody really wanted to talk to me because I just always was so down. Sometimes [the doctor] is the only person that you feel like maybe understands truly and has compassion towards your situation.

He understood when I told him how I felt, where other people didn't understand how I felt--as though it was in my head, where he knew it wasn't.

I don't really feel that anybody could understand how sick I was other than my doctor, who had seen it before in other cases, and my mother, who had also been through it. . . . I felt that he understood me and could relate to what I was going through and could help me through it. He was really the person I felt could understand everything I was going through the most, other than my mom.

In addition, others noted that obstetricians, in particular, are the most apt to provide the support and understanding necessary to women experiencing pregnancy complications such as HG. One respondent explained:

I would definitely recommend an OB/GYN in these kinds of cases, not just a regular M.D. or whatever. I think the OB/GYNs are more in tune with what's going on with a person when they are in that condition, so I don't know. That's my personal opinion. I think that's something that people might want to think about if they're having a problem pregnancy or whatever.

### Demographic Variables

Quantitatively, none of the demographic variables evaluated was found to be related to Patient Satisfaction (Table 5).

Table 5

Analysis of Variance of Demographic Variables of Interest Based  
on Respondents' and Physicians' Characteristics and  
the Dependent Variable, Patient Satisfaction

| Demographic Variable                  | <i>F</i> | <i>p</i> -Value |
|---------------------------------------|----------|-----------------|
| <b><u>Respondent</u></b>              |          |                 |
| Race                                  | .21      | .8926           |
| Education                             | .77      | .5718           |
| Income                                | 1.36     | .2549           |
| Employment                            | .95      | .4178           |
| Maternal Transport                    | 1.02     | .3159           |
| <b><u>Physician</u></b>               |          |                 |
| Gender                                | .09      | .7666           |
| Race                                  | .12      | .8862           |
| Specialty                             | .19      | .9018           |
| Length of Patient-Doctor Relationship | 1.38     | .2393           |

**Notes.** *N* = 96 for all variables except for income (*N* = 92). Respondent age was tested using regression analysis ( $r = .08$ ;  $p = .4357$ ).

However, there was limited evidence, based on respondents' comments throughout the interview, that pointed to some association between length of relationship and patient satisfaction that warrants further study. For example, with regard to the theme "believes patient's story," some women explained this was not and would never be a problem, making reference to being under their doctors' care for 5 to 10 years before the HG pregnancy. Furthermore, one woman noted the reciprocal nature of the patient-doctor relationship and the satisfaction that results from a history of knowing one another. She discussed her doctor's support and understanding of her HG experience, as well as the family problems affecting her illness, as a function of this

long-term relationship. She believed that not only was he more open to discussion, but she was more apt to open up to him because of his knowledge of her life situation. She stated:

But that's also going back nine years of knowing my history of what my life has been. It depends on where the doctor is and what level they are at with their patients. I know doctors that are running around on call aren't really into actual patients' life and times. They might not have as easy of a time getting to know the patient. In that situation, patients don't want to take the time to share with them. You don't have any energy to get into it.

### Summary

In this chapter, patients' responses were presented to clarify the patient factors that were most highly associated with patients' satisfaction with the medical care received from their doctors in the treatment of HG. Quantitative analysis provided evidence in support of Hypothesis 5: Humanism. Evidence was also provided by the qualitative results that supported associations between Causal Explanation, Seriousness, Impact, and Congruence and the dependent variable, Patient Satisfaction. Potential confounding demographic variables were analyzed, and none was related to Patient Satisfaction, quantitatively or qualitatively, although the variable length of relationship requires further exploration. The final chapter, Chapter V, contains a discussion of the research results and their implications.

## CHAPTER V

### DISCUSSION AND IMPLICATIONS

This exploratory dissertation study set out to examine patients' perceptions of the patient-physician relationship that affect patients' satisfaction with the overall medical care received from their doctors in the treatment of HG. Specifically, the researcher examined the relationship between aspects of the patient-physician relationship (i.e., Causal Explanation, Seriousness, Impact, Congruence, Humanism) and Patient Satisfaction in the treatment of HG from the perspective of HG patients. Prior to this study there had been no documentation regarding patients' perceptions about their own or their doctors' beliefs about HG, or their satisfaction with the medical care received in the treatment of HG. This final chapter includes a discussion that is presented in terms of the study's major findings; the divergence of quantitative and qualitative data: alternative explanations; the emergence of related themes; the study's limitations; the implications for practice, policy, and research; and concluding remarks.

#### Major Findings

The quantitative evidence was not strong enough to reject the null hypotheses except the hypothesis with regard to Humanism (i.e., patients who perceive their doctors as more humanistic will report greater satisfaction with the medical care received from

their doctors). The null hypotheses not rejected were the independent variables of Causal Explanation, Seriousness, Impact, and Congruence. Nonetheless, there was substantial qualitative support for the hypotheses in that respondents reported greater satisfaction when their doctors believed in a mostly biomedical etiology, believed the illness to be serious enough to warrant medical monitoring and intervention, understood the impact on the patient's life (in particular, family and employment), shared similar beliefs about each of these variables, and exhibited humanistic characteristics. The overarching themes woven throughout each of these categories were: (a) respondents were adamant that their HG was not "all in their head"; (b) they voiced confusion, frustration, and anger in situations in which this was suggested or implied by their physicians; (c) they expected their physicians to believe their accounts of their symptoms, make the diagnosis, and take action; and (d) they expected an understanding and compassionate approach by their doctors. These themes, combined with respondents' presumptions of physicians' knowledge and expertise about HG, appeared to enhance patients' trust and confidence in their physicians and contributed to their overall satisfaction with care.

In this study, the independent variable, Physician Humanism, was the only patient perception factor found to be significantly associated with patients' satisfaction with the medical care received from their doctors in the treatment of HG. This finding is consistent with other studies that have examined empathic determinants of patients' satisfaction with the patient-doctor encounter such as interpersonal warmth, respect, and information communicated by physicians (Anderson & Zimmerman, 1993; Brody



et al., 1989; DiMatteo et al., 1986; Falvo & Smith, 1983; Frankel, 1995; Hauck et al., 1990; Kenny, 1995; Schneider & Tucker, 1992; Ware et al., 1983; Wolf, Putnam, James, & Stiles, 1978). It is also consistent with scholarly works positing that empathy, compassion, and respect for patients' dignity should be a natural component of the patient-doctor relationship, not a right that patients need to demand (Gordon, 1983). Moreover, as the data suggested, these qualities ought to derive from the physician's basic caring for a fellow human being, and not merely something that happens when the doctor puts on the "white coat" (T. Tomlinson, personal communication, April 5, 1996).

The qualitative component of this dissertation added depth to the quantitative findings. The open-ended questions sought to elicit the perceptions and feelings of female patients in their own voices, thereby providing substantive content that gave meaning to the categories comprising each of the six constructs (i.e., Causal Explanation, Seriousness, Impact, Congruence, and Humanism) and the dependent measure, Patient Satisfaction.

For example, a major theme that emerged from the qualitative data was patients' perceptions of doctors' "believing the patient's story." HG patients in this study were often surrounded by family, friends, and acquaintances, not to mention encounters with other health care professionals (and sometimes the woman's own internal dialogue), who sent messages that physical symptoms were a result of "normal" NVP, that they were overreacting, and that the HG was "all in your head." The respondent who earlier described an unpleasant interaction with the specialist who informed her HG was psychological went on to explain that she remained confident during her pregnancy

because her own doctor never conveyed this message to her. She described not feeling alone even in the midst of unpleasant insinuations. Thus, a doctor's belief in the patient's story was of great import for many women. Doctors' "believing a patient's story" was essential in warding off negative and nonsupportive messages of others.

Furthermore, this researcher found that doctors' believing women with HG was always necessary, and, in some cases, sufficient, for patient satisfaction. The data demonstrated that being believed was necessary for at least two reasons. First, patients expected that their doctors would respect their integrity (i.e., that one is neither fabricating symptoms nor overreacting about minor symptoms). Second, doctors were more likely to take action if they believed the patient's story. Doctors' action to resolve and/or medically manage the HG was a desperate need and expectation reported by these respondents. These women sought medical care for a medical problem. Moreover, perceived delays in making the diagnosis and/or in instituting medical treatment were viewed as contributing to unnecessary exacerbations of the illness and hospitalizations. One woman summarized, "It's important that doctors believe you and not make you feel like you're crazy or a wimp because they are the ones that you go to for help. And if they're going to make you feel like it's your fault and it's really not their problem [medical], then we don't need them."

In addition, although not reported as necessary, respondents thought that being believed was important in the recovery process. For example: "When the doctor is working for you, you feel good about yourself. And I think when you feel good about yourself, you're maybe going to get better quicker." And "[It is important] for doctors

to understand that it's not in their [women's] heads because it is less stress and worry on top of everything . . . feeling that they understand and that they are there for you, to do whatever they can."

Patients responded to "not being believed" in a variety of ways. The strong influence of "expert power" (Todd, 1989) created confusion for some and anger for other patients when their inner sense of what was actually happening was incongruent with their perceptions of their doctors' beliefs. A few women remained with their doctors despite "not being believed"; they focused their attention on the positive aspects of their doctors' care and sought emotional support from other people. Others experienced diminished self-esteem as they questioned themselves (e.g., "Maybe I am not trying hard enough," and "Maybe I am overreacting."). Other literature has shown that some women tend to devalue their own insight and do not listen to their inner voice, in part, due to gender socialization. For example, women who believe that they are "receivers" of knowledge defer to others, especially to those in authority (Belenky, Clinchy, Goldberger, & Tarule, 1986).

Although physicians' expert power was often quite influential for patients and members of their families as they looked to the doctors for guidance, still other patients who perceived they were not believed became frustrated and angered. Dissatisfied with the medical and/or psychosocial care of their physicians, some of these patients never returned to their previous doctors (e.g., from the prior pregnancy); others changed doctors in the midst of the HG pregnancy of interest for this study.

In addition to being necessary to patient satisfaction, the patient-doctor relationship was sometimes sufficient, especially in the realm of support in coping with HG. This relationship served as a protective shield of sorts; the belief that "my doctor believes I'm really sick" armed patients with the confidence necessary to defend themselves against the skepticism of others. Doctors' beliefs were instrumental in empowering patients with confidence. Moreover, doctors' affirmation and confirmation of the patients' experience often led to family and friends coming on board, offering the necessary validation and support of the illness experience.

However, in cases where it did not lead to changed attitudes among others, and especially for women who had a limited and/or a nonexistent social support network, the patient-doctor relationship was often sufficient in getting women through the illness experience. When patients felt the backing of their doctors (e.g., "on the same wave [length] together"), they were able to acknowledge the illness experience that they intuitively knew to be true. Moreover, being believed avoided the need for women to struggle to "prove themselves" to their doctors and to others. The essence of many of the qualitative comments was such that "if my doctor believes me, that's all that really matters." This finding is consistent with scholarly works advocating the value of professional support as an important form of social support (Crnic, Greenberg, & Slough, 1986), and physician empathy as a major determinant of patient satisfaction (Frankel, 1995).

Furthermore, some patients perceived their doctors as the only persons who truly understood the physical and psychological toll HG placed on them. "Only my doctor

really understood" was a dimension of the patient-doctor relationship central for some women with HG. This theme emerged from the qualitative data, capturing a phenomenon that the study's quantitative measures were not designed to elicit. In this study, women viewed their own doctors not only in terms of the key medical role, but also as key psychosocial support persons. "Only my doctor really understood" speaks to the unique importance of the unit of analysis in this study--the patient-physician relationship. This is an important finding in light of the pervasive literature that suggests physicians historically have demonstrated insufficient appreciation and understanding of women's experience with illness, and about HG in particular.

Finally, the finding that the majority of respondents in this study were "satisfied" with their doctors demonstrated that the patient-physician relationship worked most of the time for most of these women. However, when it did not work, the experience was unforgettable, contributing to patients' reports of diminished self-confidence, delayed recovery, and discontinuation of their doctors' care.

#### Divergence of Quantitative and Qualitative Results: Alternative Explanations

Except for Humanism, the quantitative and qualitative results of this study told different stories with regard to various aspects of each of the independent variables. Following is a discussion of alternative explanations for the divergence of these findings that the quantitative evidence was not strong enough to reject the null hypotheses with regard to Causal Explanation, Seriousness, and Impact. The Congruence variable, comparing doctor-patient beliefs, will be embedded within these three as appropriate.

In addition, interpretations of the results regarding Humanism and Patient Satisfaction will be presented.

Causal Explanation. In reviewing the data, a few possible explanations emerge that support the findings of no significant relationship between patients' perceptions of their doctors' beliefs and Patient Satisfaction. First, quantitatively, the values on most Causal Explanation items were relatively high, reflecting a mostly biomedical belief. Comparing this to qualitative comments suggests a relationship between Total Causal and Patient Satisfaction.

One exception, however, was the influence of one item in the variable set. Item 4, which referred to the hereditary nature of HG, was constructed to reflect a biomedical belief. Because 68 of 96 doctor belief responses were *disagree* (e.g., that HG is genetic), and qualitative responses concurred as there were only a few comments about a genetic factor, this created generally low values for this item, which may have influenced the overall hypothesis that high scores on biomedical would be associated with Satisfaction. With the exception of the item regarding heredity, which may not belong in this Causal set, the qualitative comments clearly point to a positive relationship between Causal Explanation and Patient Satisfaction. Patients reported greater satisfaction when their doctors believed in a mostly biomedical etiology for HG.

Some qualitative comments demonstrated why low scores on Causal Explanation were, in fact, related to Patient Satisfaction. Some women reported overall satisfaction with their doctors but voiced displeasure when the doctors implied a psychological component (e.g., low values). For example, one woman voiced confusion about her

doctor's response; yet because this was a one-time incident, she did not necessarily allow the negative encounter to influence her overall *very satisfied* score with the care received. She explained:

The only thing I ever really got upset about was when I was released home, he had told me to drink broth and that sort of thing. We made up some with bouillon and I got sick on it. And he put me back on the phone with him, and he said, "Do you want to be hospitalized again? You've got to stop doing this." And that, to me, was kind of a slap in the face, like I had a choice to be sick. I think he thought it was just all in my head at that point maybe, I don't know. I didn't [get the feeling from him that he thought it was in my head] until that point when he said that to me . . . and I thought, "Like I have a choice? I don't have a choice in this matter. I'm sick because I'm sick, not because I want to be sick." So up until the end, that was the only incident that he was ever that way with me. . . . [I felt] like he thought I was just full of it.

Additionally, relatively low doctor belief scores on Causal I ( $M = 2.71$ ) compared to Causal II ( $M = 3.29$ ) may have contributed to the results. As perceived by the patients in this study, doctors' beliefs for the general population were "mostly psychological" compared to their "mostly biomedical" beliefs about their own patients' HG. Similarly, patients' beliefs about Causal I were lower than Causal II as respondents were reluctant to generalize from their own experience to other HG women. That is, they knew that their own HG was "not in their head," but believed that there were probably some women, albeit few, whose HG was the result of psychological or stress-related problems. Thus, lower Causal I scores for patients' perceptions of doctors' beliefs affected the overall Total Causal score (as well as impacting Congruence: Causal Explanation for doctor and patient beliefs), such that a statistically significant relationship between Causal Explanation and Patient Satisfaction was not found.

Moreover, concerns regarding the reliability of the items comprising the Causal I: General subscale for both patients' and their perceptions of doctors' beliefs are apparent. Despite an acceptable overall reliability coefficient (.7519) for patients' perceptions of their doctors' beliefs about Causal Explanation: Total, analyses of the individual subscales comprising Total Causal showed that the reliability coefficient for the subscale Causal I: General was quite low (.3169). This indicates poor internal consistency for the five items comprising this subscale. Similarly, the congruence variable was likely affected by both the questionable reliability of doctors' beliefs for Causal I as well as the very low reliability coefficient (.0207) for patients' beliefs on the Causal I: General items.

A third possible explanation is that patients' reports of high scores on doctors' beliefs suggesting a biomedical etiology may have been affected by physician Humanism (Hypothesis 5). It was hypothesized that higher scores on biomedical belief items would be positively associated with Satisfaction. In some cases, perceptions of doctors' beliefs of a mostly biomedical etiology were irrelevant to patients if, in fact, doctors demonstrated poor humanistic qualities. For example:

He was just rude and short. It seemed like I was bothering him if I would talk to him or anything. . . . It felt to me like he didn't care, like he just wanted me to tough it out, and that was hard. [I didn't get the sense] that he necessarily thought it was in my head, but that I wasn't trying my hardest to try and keep fluids down. The impression I got was that I should have been trying harder. [I felt] frustrated; I just wanted to scream.

Seriousness. Despite the quantitative finding of no significant correlation between Seriousness and Satisfaction, the qualitative comments generally suggest that patients were, in fact, more satisfied when their doctors viewed HG as a serious



condition that required medical attention. This conclusion was drawn from both the large number and substantive quality of the comments made about "physician monitoring." Respondents clearly interpreted physician monitoring behaviors as doctor beliefs that HG was serious or had the threat of becoming more serious. In addition, respondents were clear that they were satisfied when their doctors viewed the intensity of their symptoms as serious versus a nuisance that must be merely tolerated as a normal occurrence of pregnancy.

Possible explanations as to why the hypothesis was not supported quantitatively are provided in the data. First, both quantitative and qualitative data showed that patients generally thought their doctors believed there was little serious risk to patient or baby. Patients' perceptions of these doctor belief values were low on scale items (e.g., "My doctor believed that my HG was a serious condition," "My doctor believed that I could have died from HG," and "My doctor believed that my baby could have died because I had HG") possibly because this *was* the medical reality for many of the respondents. That is, HG did not manifest itself as seriously for some women as for others and, therefore, did not pose a serious threat to the life of mother/baby. Thus, the hypothesis that higher Seriousness scores would be associated with higher Satisfaction scores was not borne out by the data. Even though patients' comments point to a perception that their doctors viewed HG as serious overall, they did not necessarily report doctor beliefs that their, or their baby's, health and/or life were in danger.

In comparing patients' beliefs and perceptions of their doctors' beliefs reported in the interviews, many women described their fears and worries about their own

physical health as well as the health of their babies. However, they reported that the medical care and reassurance provided by their doctors instilled confidence to the extent that they questioned whether their fears were inaccurate perceptions of the objective state of medical reality. That is, the anxiety, worry, and concern the respondents, as pregnant women, experienced for themselves and their unborn babies did not necessarily mean that there was actual medical danger. Thus, a respondent may have reported a belief that she/baby could die from HG, yet reported the opposite doctor belief because she trusted that her doctor, with an extensive medical training and a history of treating HG patients, had a more complete understanding of the biophysiological status of her condition.

In addition, individual patients' beliefs about Seriousness were greater or lesser depending on the severity of the symptoms and the invasiveness of the medical treatment employed. Most respondents equated admission to the hospital and administration of intravenous fluids as "serious." Some interpreted these actions to mean that their doctors thought their situation was quite serious. Most, however, interpreted these actions as indications that their doctors took the illness seriously and were taking action, but not that there was grave danger or risk of death for mother/baby. Because the women realized that these treatment interventions are considered standard practice (as opposed to extraordinary measures) by physicians, they reported doctor beliefs as not as serious as their own beliefs.

Additionally, it can be speculated that doctors did, in fact, view the illness as serious, hence active monitoring behaviors; however, informed patients of no risk of

danger to mother/baby in order to decrease anxiety, maintain hope, and attend to the psychological needs of high-risk pregnant women. Again, this could account for the lack of a statistically significant linear relationship between Seriousness and Satisfaction scores. The Seriousness rating in no way predicted how satisfied patients were with the care received from their doctors.

A second explanation was exemplified by the respondent who voiced her disappointment in her doctor's casual and discounting attitude. She expressed her dissatisfaction with his attitude yet reported overall satisfaction with her care. Thus, some women voiced their displeasure with their doctors' attitudes and behaviors as reported by lower ratings on their perceptions of their doctors' beliefs on the Seriousness item (e.g., "My doctor believed that I needed close medical attention for my HG."), yet overall, reported satisfaction with the care received from their doctors.

Finally, as discussed in Chapter IV, a distinction emerged in the qualitative data that sheds further light on why the relationship between Seriousness and Satisfaction was not supported quantitatively. Women's comments pertaining to the Seriousness construct delineated their perceptions of their doctors' beliefs about *viewing HG as a serious illness* and *taking the illness seriously*. However, some items pertaining to the seriousness of the illness (i.e., Item 11: serious condition; Items 12-13: threat to patient; Items 14-15: threat to baby) were constructed with the assumption that physicians' perceiving the illness as serious would lead to its being taken seriously by them, resulting in enhanced patient satisfaction with care. Although this presumption held true for most of the respondents, some women perceived their physicians' belief that HG was

not a serious illness, but still took its symptoms and the patient experiencing those symptoms seriously. For these respondents, it seemed much less relevant to the women whether their doctors thought HG was a serious illness; what mattered to them most was that doctors respected their concerns about the illness and took action.

**Impact.** Following are alternative explanations for the lack of statistical support for this hypothesis. First, some respondents discussed Impact in relation to their doctors' attitudes and behaviors that were not particularly helpful, yet these perceptions did not negatively affect their overall level of satisfaction. For example, one woman described that her doctor neglected to address discharge planning issues that would facilitate the patient's timely release from the hospital in order to relocate with her military husband, as was mandated by the Army. She reported overall satisfaction with her doctor, despite feeling that her doctor did not fully appreciate the serious implications for her life and family that were magnified by the hospitalization. Thus, a similar pattern, also noted earlier with regard to Seriousness, was present for Impact. That is, women expressed dissatisfaction with Impact-related issues, leading to lower values on scale items, yet still reported overall satisfaction with the care they received.

Second, the fact that the majority of women's comments did not attend to doctors' beliefs about Impact (except for employment and family issues) corresponds to the quantitative findings. Qualitative comments suggested that some patients may welcome, but did not necessarily expect, their doctors' pursuing Impact-related issues. Moreover, some women did not appear to need this type of dialogue with their doctors; they explained that they would not seek out the assistance of their physicians for

nonmedical issues. However, high scores on the Humanism scale (which incorporates items about Impact) demonstrated that most respondents did, in fact, perceive that their doctors had a fairly good awareness and understanding, albeit to a lesser extent than the respondents, regarding the disruptive nature of the illness (e.g., lost wages, children being shuffled among many caregivers, learning complex home care equipment, etc.).

In comparing doctor-patient beliefs, patients' scores on Impact were higher, possibly due to the reality that only they, having lived with the illness, could have the greater awareness of the impact on their lives. This speculation is supported by the data, which showed numerous comments about patient beliefs about Impact (e.g., occupational, day-to-day, social, and family functioning), yet few comments regarding doctors' beliefs about this subject. Women noted the variety of ways that HG impacted patients' lives, with the overwhelming response being that HG interfered with, and negatively affected, their daily lives.

Humanism. This study, consistent with the findings of Hauck et al. (1990), found that patients' perceptions of their doctors' humanistic characteristics led to greater reported patient satisfaction. In light of the high .60 correlation ( $p = .0000$ ) between Humanism and Patient Satisfaction as well as numerous comments reflecting much satisfaction, it is curious that Humanism scores did not result in the value of *strongly agree*. As discussed in Chapter III, caution should be taken not to overread why there was not strong agreement reported on Physician Humanism, especially as individual patients vary in their expectations of the patient-doctor relationship. Many of the respondents who reported being *satisfied* (vs. *very satisfied*) on the Humanism

scale expressed greater satisfaction when they elaborated on their relationship with, and care received from, their doctors on the Client/Patient Satisfaction Questionnaire.

**Patient Satisfaction.** One alternative explanation for the relatively high level of satisfaction (e.g., *mostly satisfied*:  $M = 3.63$ ;  $Mdn = 3.87$ ) found in this study emerged in the qualitative data. Respondents who described unsatisfying interactions with their doctors were often quite forgiving of these incidents. One-time distressing incidents, in particular, tended to be ignored, albeit not forgotten. Even when patients reported overall satisfaction, they could vividly recall the "bad" incident, although they did not allow it to negatively color their overall opinion of the care received. Most of the women in this study acknowledged not only the limitations of medical science, but also that doctors are "only human." They also reported an appreciation of doctors' busy schedules and the demanding nature of their work. Thus, the women in this study did not expect their doctors to be perfect. However, they did expect their doctors to believe their stories, treat them in an empathetic manner, and make an active and sincere effort toward managing the illness even in the midst of no cure.

In addition, other literature (Larsen et al., 1979, p. 200) has demonstrated that high patient satisfaction scores may be the result of "grateful testimonials." With regard to perinatal research, the outcome of the pregnancy (i.e., a healthy baby) could retroactively influence patients' perceptions of how satisfied they were/are with their physicians. This may have been a factor here, although it was not explicitly mentioned by any respondent. Furthermore, there is some evidence to suggest that women

generally report higher levels of satisfaction compared to men (DiMatteo & Hays, 1980), which may have implications for interpreting these results.

Despite an overall rating of *mostly satisfied*, it is surprising that the CSQ-8 did not yield a mean score of *very satisfied* based on the large number and substantive nature of the qualitative comments. An apparent discrepancy was observed when some respondents expressed *very satisfied* qualitative comments about their doctors, but reported less than *very satisfied* values on the CSQ-8. Some women noted, however, that lower values on particular items (e.g., Item 3, "To what extent did your doctor meet your needs?" and Item 5, "How satisfied were you with the amount of help you had received from your doctor?") reflected their dissatisfaction with medicine's lack of understanding about, and lack of treatment for, HG. Some explained that they were unable to answer *very satisfied* on the CSQ-8 because of the lengthy duration of the illness combined with what they perceived as "experimenting" with various medical treatments. They qualified their less than *very satisfied* quantitative response indicating slight dissatisfaction with the overall medical care given as a result of the shortcomings of medical science and humankind. That is, respondents reported the limits of medical science (e.g., no known cause or cure) and human limitations (e.g., "doctor is a human being, not God") as partial reasons underlying a decision to respond *satisfied* versus *very satisfied*.

In contrast, the finding of *mostly satisfied* for this sample of HG patients may have been skewed toward more favorable satisfaction results for the following reasons. The respondents were asked to think about only the doctor who took care of them the

most during the course of their illness on the quantitative measures. Qualitative data suggest, however, that respondents did not necessarily report satisfaction with "other doctors" who treated them for HG, but with "their own" doctors. Dissatisfaction with "other doctors" (see *Beyond Major Findings: The Emergence of Related Themes*, p. 140) was noted as an additional theme but is not reflected in the primary data based on the design of the study. Patients' experiences with their own doctors were more positive than their experiences with "other doctors." This may be due, in part, to the relationally based rapport with their own doctors as opposed to brief encounters with other doctors (e.g., emergency room, doctor's partners).

Furthermore, "the doctor who took care of you the most" was not necessarily a respondent's primary care physician (e.g., cases of maternal transports or referrals to subspecialists, e.g., perinatology). However, for almost half of the respondents this was the case; 43 women were under the care of their primary care physicians for two or more years before the HG pregnancy of interest in this study. (Note: There are probably more primary care physicians referred to in this study; however, the number of respondents whose length of relationship with their primary physician was less than two years cannot be determined from the data.) Although not found to be statistically significant, the possibility is raised that satisfaction is a function of knowing one's doctor for many years. The long-term nature of this relationship presupposes that the patient is satisfied with her doctor. Other literature has shown that patient satisfaction is positively related to the length of time a patient is under the doctor's care due to the "familiarity effect" (DiMatteo & Hays, 1980, p. 31).



In addition, these women in particular were able to choose the type of doctor with whom they might be most satisfied (e.g., based on physician gender or expertise within the community). This introduces, for example, a possible preexisting correlation between physician gender and patient satisfaction that the study was unable to delineate. Respondents with a short-term relationship with their doctors before the HG pregnancy of interest may have chosen their physicians, but it is also possible that they were assigned based on an inpatient hospital attending and/or specialist rotation system, prenatal clinic resident rotation system, or their primary physicians' preference/referral based on an HMO's preferred providers.

Similarly, a few of the "other doctors" noted were originally the patients' "own doctors," but due to dissatisfaction, the patients changed before the pregnancy and/or in the midst of the HG pregnancy. Dissatisfaction with these doctors--by women who refused to tolerate what they perceived as poor care--is not reflected on the CSQ-8. The CSQ-8 reflected their beliefs about the doctor whom they changed *to*, based on physician characteristics they thought would be satisfying. Choosing one's doctor may already have some quasi-guaranteed degree of satisfaction in it.

#### Beyond Major Findings: The Emergence of Related Themes

Although this study was designed to elicit data about physicians who took care of respondents the most during the course of their HG illness, additional qualitative data related to the research questions in this study were analyzed. These additional data are relevant because they provide further support for what the study hypotheses suggested about the patient-physician relationship but that the quantitative instrument

was not designed to document. These data also provide important information about the various contexts of HG patients' experiences with others that goes beyond the patient-physician relationship.

Specifically, this section contains selected excerpts derived from the qualitative data pertaining to respondents' experiences with other health care professionals and the lay community. The purpose of this section is to highlight the finding that, despite respondents' overall satisfaction with the doctors who took care of them the most, women's narratives demonstrate the significant roles, both positive and negative, played by others during the course of HG. As with women's perceptions of the doctors who took care of them the most, "believing a patient's story" and "taking the illness seriously" were the primary themes for these additional two groups.

### Health Care Professionals

Other doctors. Most of the respondents mentioned other physicians they encountered during the course of their HG. With the exception of a few positive comments, respondents expressed numerous negative experiences with these other doctors. "Other doctors" can be categorized into seven groups: (a) partner(s) of the doctor who took care of women the most, (b) previous doctors (whom respondents changed from due to dissatisfaction), (c) interns and residents, (d) emergency room doctors, (e) specialists, (f) new doctors (transferred care due to relocation), and (g) other women's doctors.

The themes "believes patient's story" and "taking the illness seriously" encompassed respondents' reports of dissatisfaction with what they perceived to be

doctors' lack of concern, punitive messages, misinformation regarding HG and treatment strategies, and delayed intervention. Respondents attributed these factors most frequently to being a result of doctors' beliefs that HG patients were overreacting and/or that the HG was psychological and, therefore, did not require medical attention. Following are examples that illustrate women's negative experiences with other doctors.

The first time I went into the hospital I was quite sick . . . and they had given me maybe a half a day of drugs, but really what happened was there was a mix-up on the order and I received IV therapy, but no nausea drugs. And she [doctor's partner] came storming in and said, "You should not be this sick, you have already had your nausea drugs." Well, as it turned out, I didn't. My mother-in-law straightened it out and said nobody came in and gave me nausea drugs or put anything in the IV; and it turned out nobody had. But, I mean, she grabbed that basin away from me and said, "You should not be throwing up like this any longer."

There was another doctor in the practice that I was not very pleased with. I think he thought it was in my head; he was just real sharp, "Why are you throwing up? Have you tried to stop?"--that type of thing. He's an OB, and he should know that you can't stop once you start. I really think that particular doctor just had no compassion.

At one point an intern came in and spoke to me, and he kind of made me feel like I was bulimic or something. He kind of made me feel like I wasn't trying to eat or drink. And I think that was the only time anybody ever made me feel like this was my fault. I don't know if it was the way he said it or my reading between the lines, but he kind of made me feel like I was making myself be this ill. He figured I should be able to stop this, and that just infuriated me because that was the second time I was hospitalized, and I felt like "Don't you understand? I don't want to be this sick." I had a little boy at home who was not even three years old yet. I mean, I had other things to be thinking about. . . . So, I mean, it certainly wasn't something that I feel I even remotely brought on myself.

I had an ER doctor tell me that I should never have gotten pregnant again because people have "only children" because they have hyperemesis the first time, and why would I do this again? [He thought] I should've stopped after one. I started crying hysterically because I'd been in there [a long time]; so he admitted me and told me I wasn't dealing well with the pregnancy. [He said] I needed to see a psychiatrist, and that was what he admitted me for. [Note: This

woman's doctor rounded the next day, expressed confusion regarding the hospital admission, canceled the psychiatric referral, and discharged the patient.]

I had to go to a specialist because I had a lot of other problems besides the hyperemesis. I was so sick. He explained to me why I was feeling this sick is because some people, their minds. . . . He more or less said it was in my mind. [I was not happy with him] because I knew that it wasn't in my mind. I wasn't stressed until I got sick. Nobody would want to be that sick. Plus I needed . . . I planned on working up until I gave birth, for the money. So there's no way I would just. . . . It's just not in my mind. . . . I just saw this guy one time. But then I didn't like him, so I didn't want to see him again.

Respondents' negative experiences with other doctors are further exemplified by nine women who reported that they either changed doctors for their subsequent pregnancies or in the midst of the HG pregnancy of interest for this study due to dissatisfaction with care. In the words of one respondent, "If you don't like your doctor, switch. If your doctor doesn't seem to understand or is not taking the actions you feel need to be taken, then definitely switch doctors because I don't think all doctors do have an understanding." Other comments in this vein included the following:

I had a doctor before that didn't believe me that I was so sick.

The first doctor I had tried to act like I was depressed or had family problems. He had a psychiatrist see me in the hospital. It was not helpful. I knew it wasn't in my head. And the doctor tried to act like I needed to get up out of bed and move around, that I'd feel better. He'd come in and open the shades, you know, with the bright light right in my eyes. And that just makes you feel worse. When you feel sick and you have a terrible headache. I just wanted to be left alone to try to sleep or lay down or whatever. And when you have someone bossing you around, it doesn't help any to be bossed around when you feel like that. No one likes to be bothered when they have the flu. You know, that's basically what it's like, having a bad case of the flu for nine months.

The doctor just seemed to think, "Live with it." He wouldn't give me any time off from work or anything like that. I didn't know what was wrong with me because other people that were pregnant with me didn't have those problems [HG]. And then I started thinking, well, maybe it's me, and then when I would

see the doctor I just wouldn't even bother mentioning how sick I was or anything because there was no point.

In addition, some respondents also were grateful for their positive relationship with their own doctors and talked about the stories they had heard from other women who had had negative experiences with their doctors.

I was surprised at the number of people that told me that their doctors told them that it was all in their heads. I cannot believe that a doctor would actually say that. I had a coworker who told me her doctor (who happened to be a male) said that it was all in her head and would not even write her a note to miss work.

I've heard a lot of women say that the doctors don't understand; and that was real hard for me at first because my doctor was understanding.

In talking to some of my clients, the doctors think that they're hysterical, and they really don't want the baby and all this crap, which is just crap.

I know a woman from my church whose physician admitted her to the psychiatric wing, had her under psychiatric care because he was a guy from the old school, and he just thought she was nuts. It was really destructive to her. I think she still deals with it, and her little girl is probably about six. [She didn't feel she needed it at all], and she felt that even though she thought it was physical, she was being told that it was in her head. So she was kind of beat down in her self-esteem. She just had a lot of negative, hostile feelings about that whole experience. So, you know, I'm telling you the best picture [e.g., respondent was very satisfied with her doctor].

Hospital nurse. Many of the study participants cited nurses, both in the hospital and in doctors' offices, as being just as integral as, and sometimes more integral than, their doctors in the treatment of HG.

I know that the main support for me, the main understanding, the main care comes from the nursing staff. It's not the doctors, it's the nurses . . . in the hospital. And when you call the doctor's office, you don't talk to the doctor, you talk to the nurses. The nurses have the main part to play in your care of this. In the hospital, for instance, they're far more involved in you than the doctor. They're the ones that are in every hour. They're the ones that change your medications, who help you to the bathroom, who clean up your vomit. The doctor doesn't do any of that. The doctor pops in in the morning, asks you how

you're feeling, talks to you a few minutes, and then he's gone. It is the nurses that provide the care and support, and I mean support in capital letters because that is the best group of ladies I have ever met in my life. And the nurses in the doctor's office, too. When you call, they are who you talk to. They are who call you back, so that's what your contact is most of the time is the nursing staff.

A few women talked about their apprehension about being hospitalized in terms of possible negative reactions from the nursing staff. Before having a clear understanding of HG, and linked with the patterns of "second guessing" oneself, they reported feeling somewhat embarrassed that they were being admitted for what appeared to be simple "nausea and vomiting." They entered the hospital fearing hospital staff might question whether hospitalization was necessary for symptoms that appeared to be something that most pregnant women cope with and are not hospitalized for. One respondent noted the relief she experienced as a result of hospital nurses' validating the illness and need for hospitalization. She explained:

I think that the nurses, actually, were really great. I didn't know whether they would think it was stupid for me to go in there [hospital] or what, but they were very, very good to me. They felt bad for me and everything. You don't know what to expect when you go into [the hospital] and don't know whether they think it's real or not.

Another woman found comfort in a nurse who had, herself, experienced HG. Receiving validation and support from this nurse as well as other hospital nurses empowered this respondent. By enhancing her confidence, the patient felt as if she could take control of managing her illness. She remarked:

Once I found out that it wasn't normal and that I was really sick and when I went into the hospital, I had one specific nurse that came in. She said that she had hyperemesis, and said, "Nobody knows what it is like until they have been there." That just made me feel like I was not crazy and that I could handle it. It was easier once I got out of the hospital, because I felt like I wasn't crazy, and I was very sick; and it was very serious.

In contrast, patients expressed dissatisfaction when they "got the feeling" that staff members believed their symptoms were not "real," or that the patient was not "trying hard enough" to get better.

I didn't throw up as much in the hospital because I was on the diet, and plus I had the Phenergan. I didn't throw up as much in the hospital as I did when I was at home. One of the nurses made me feel like I was kind of faking it. But I think that was only one nurse on one shift. I didn't feel that in general.

Dissatisfaction also ensued when respondents did not feel nursing staff understood the nature of HG and the coping strategies necessary to manage the nausea and vomiting. Most respondents described the need for low environmental stimulation (e.g., movement, light, noise, smells), especially during the acute phase of the illness. One respondent pointed out her need for low stimulation, something that she thought nurses did not understand. She explained:

The nurses [need] some sort of insight into what you're going through because I became very frustrated with them. They would come in and flip on the light. I mean, that alone could make me throw up. I laid in a dark room. I hung three sheets over the window. There were a couple of really good nurses. The majority just didn't seem to understand. I don't know how you make someone understand something that they've never been through, but. . . . Or talking really loud like you're a million miles away. And it's like you can barely stand listening to it. Any type of stimulation, light, movement, sound--everything is just, you just can't tolerate it.

This lack of understanding was discussed not only in terms of lack of empathy, but also linked to what respondents referred to as "threatening" behaviors. One woman noted what she perceived as punitive behavior by staff in their attempt to motivate her to eat more:

They kept telling me that if I didn't eat they were going to have to put the tube in my chest to feed me, and it made me really scared. They left the kit laying right by my bed for a couple days. That really scared me, and I didn't really like

that; but everyone else thought that really helped me to make myself try to eat. . . . Like all my family members thought that it pushed me to try to get better. [It did not] encourage me [to eat more]; it scared me.

Physicians' office staff. Numerous respondents noted the important role the office staff (e.g., nurses and secretaries) played in the treatment of their HG. For some respondents, these health care professionals played quite a significant role; women explained that it was often the nursing and secretarial staff in their doctors' offices--not the doctors--with whom they had the most contact during the weeks and/or months of their HG. As was discussed under Hypothesis 5: Humanism, believing the patient's story, taking the illness seriously, and taking action were themes associated with this group of health care professionals as much as they were for doctors.

Respondents noted the importance of a nurse's "bedside manner" and provided accounts of both positive and negative encounters with office nurses. Office staff were often viewed as an important, positive support network. One respondent described the office staff as "my rooting section." Another described the emotional support received from the office secretary, noting, "Even the girl that answered the phone was really concerned."

Other respondents, however, voiced their complaints about negative encounters with office staff. Specifically, the role of secretary and nurse, coded as "gatekeepers," was a predominant pattern. "Getting past" the secretary and/or the nurse was a major feat for some respondents and was viewed as a barrier to the doctor.

I didn't find that [I had to prove that I was sick] as much with my doctor or even his personal nurse, but it was with the office people, the people who answered the phones. It was them that you had to really sell yourself that you were sick. I mean, they're the ones that get you through to either the nurse or doctor.



I always felt like once I got past the nurse and I could get in there and speak to him [doctor] directly, I felt a little better.

I would call [the nurse] in the morning telling her that I was severely nauseated. I couldn't even get into the shower because I was so weak, and she just had a really, really bad attitude. She kind of tried to blow me off. She told me to have soda crackers next to the bed. And I remember even then, before I even knew what hyperemesis was, that I knew in my mind that I did not have morning sickness because mine was 24 hours a day, 7 days a week, for a very long time. I remember her telling me, "Just give it a couple more weeks and it is going to pass." And I am thinking to myself, "I don't think so." I think now, looking back, a lot of those times that I called the office and spoke to her, I think a lot of that was not reported to my doctor. Because I would go in the next month after it had been three to four weeks, and he would ask me how I had been, and he always seemed really surprised to hear my answers. So I always felt like she was just totally blowing me off, and she didn't even want to bother him with my messages or anything. And I had never been pregnant before, so in a way she probably deals with people like that, but I don't think she should have automatically assumed that I was overreacting.

Echoing reports of their doctors' altered responsiveness from the first to subsequent HG pregnancies, women described how the office staff were more supportive during "the second time around," as if the symptoms were now more "real" because of their established record of getting HG. One respondent compared the varied responsiveness she received from the office in her first and second HG pregnancies. She recalled:

I'll never forget the one time I walked in [with my first pregnancy]. They had said, "Well, why don't you come in, and we'll check you out." I was totally dehydrated, and they said, "Oh, wow, you really *are* sick!" [I wanted to say] "No, I'm just lying. I painted my face green on purpose just because I want to." That was kind of hard. [I felt] like I was a loser. And, you know, actually you feel like you're doing something wrong at that point. "Have I done something wrong to be this sick?" And that happened even really before I actually saw and talked to the doctor. [I got mad] a couple times, and my husband was the same way. Twice he ended up calling and saying, "Now look, she's really sick. She needs some help." That was for the first pregnancy; by the second they knew. It's funny, when it came time for my second pregnancy they treated me a lot differently.

Hospital social worker. As previously noted in the discussion of Hypothesis 5: Humanism, a theme that emerged from the data regarding ancillary psychosocial support services was respondents' recommendation that referral information be given to patients regarding counseling and support group services. Many noted that they might have benefited from seeing a social worker in the hospital. One woman was appreciative that her physician referred the hospital social worker to address marital stress, despite the fact that she chose not to disclose the severity of the physical abuse she endured.

In contrast, the respondent who earlier noted her frustration that her doctor referred the hospital social worker without first discussing either his concerns or the referral with her, expressed her irritation with what she perceived as the social worker's probing for psychological causes for the HG. She elaborated:

I think the questions the social worker was asking made me believe that either with some people it could be . . . psychological stress related and, therefore, maybe could be prevented; and if it's something that could be prevented, then you almost feel like you have to take responsibility. If it's nothing that can be prevented, it's, you know, divine. . . . You can't prevent it, so you just have to let it take its course. You can't look back and say, "I could have done something different." There's nothing I felt like I could have done different. When I did talk to the social worker, I was irritated because I thought maybe she thought that it could have been prevented if [I did] this or [that]. I don't know what she was looking for, but the questions did irritate [my husband and me] . . . and the fact that she thought that it could be psychological, and, therefore, if things were different maybe it could have been prevented.

### Lay Community

Family, friends, general public. Family support was reported by respondents as important to their coping with HG and their recovery process. One woman stated, "I

have a great loving, warm, caring family and a wonderful husband; but you almost have to have that because you need it. I feel bad for women who don't have that." Others articulated the extent to which their family members offered both emotional and practical assistance.

My family, both my husband's and mine, were very helpful because I had two little ones at home. So, they really stepped up and never minimized the way I was feeling either.

[My husband] didn't quite get it, but he was still really great. He took really good care of me, but I don't think he quite understood. But he knew that I was really sick, and he never made me feel like I was faking it or that I could do more.

It was even hard on my husband because he was working all day, and he would have to come home and take care of me and my daughter; and that was hard. Sometimes he would have to help me up, and he would have to wrap my arms because I had the IV in, help me to the bathroom because I was so weak he was afraid I was going to pass out. He did a lot. Boy, I was glad he was here. Because he did everything. He did everything that I couldn't do. He did all the housework. He did the cooking. He did it all. He did everything. Got my daughter dressed for school and combed her hair. He did everything.

My mom would come over and wash my hair and braid it because I was too weak and sick to do that. And my brother would come and help me clean my house and stuff, do my dishes. Everybody was really good.

Still, as was seen with some of the respondents' own physicians and other health care professionals, the respondents were definite in their accounts of finding themselves in a position of needing to prove themselves to others in their social world. Validation, understanding, and support were sometimes viewed as a function of others' knowledge of the patient's personality before HG. For example:

I had a tremendous outpouring of support from neighbors and family, because it wasn't my history; they knew once they saw me that I wasn't kidding.

Still, others noted confusion and a sense of betrayal at family members' lack of understanding.

I remember my mother thinking that I just needed to get over the fact that I was going to get fat and get on with it or whatever. I remember her saying that to me and my dad backing her up on that. And I said, "If you think that I am waking up in the middle of the night out of a dead sleep to go and vomit because there's something wrong with my head, you are absolutely. . . ." [She thought I was] watching my weight. My parents for sure [thought it was psychological]. And I'm very close to them, and they just couldn't believe it. I remember my sister coming in one time . . . and saying to me, "I just wish you'd get over this." "Well, I tell you what, I do too." . . . It made me feel angry because it makes you feel as if you are not a strong person and that something mentally is wrong with you that you could do this to yourself. I was very angry because I felt like I don't even want to be around you people because you're not helping.

Also, the pattern of having to "prove" oneself during the first pregnancy was found with family and friends as it was with doctors and health care professionals.

To be honest, my husband, I think, was one of them [who thought I was overreacting]. And I say that only because when I had my second, I think he maybe realized, "Wow, this is for real." He would probably say no, he didn't think that, but that's the feeling that I got.

In addition, some respondents described the reactions of others (e.g., family, friends, employers) as expecting women to continue their roles as wife, mother, and employee even in the midst of their illness.

We had only been married 1-1/2 years before I got pregnant. And his family [caused the most stress] because my housework suffered and I wasn't taking care of my husband . . . and his family was having a hard time with that, that it [HG] was a problem. They didn't understand why I couldn't do those things. And we didn't get any help from them.

It is possible that these unrealistic expectations are, in part, due to another pattern that is reflected in the women's narratives. There was a pattern pertaining to the perception that pregnancy is not an "illness"; pregnant women are not "ill" women.

That is, they are women encountering normal physiological symptoms associated with pregnancy. And although this pattern was noted with regard to doctors, health care professionals, and, to some extent, the patients themselves, lay people were noted as most susceptible to this belief. This finding is consistent with studies of NVP suggesting that the validity of symptoms are challenged by family, friends, and caregivers (O'Brien & Naber, 1992). Perhaps this is because NVP is the most common and well-documented physical symptom of early pregnancy, and to the lay person, HG resembles NVP.

People say you're just having nausea, you know, people had that years ago. But this is 24 hours a day, and you can't even keep your own saliva down. There's a difference between being morning sickness and hyperemesis. People didn't understand it, so they took it kind of loosely. Almost [like saying], "you're just such a baby. You should just deal with it." You're throwing up your stomach bile, and you're throwing up blood; it's not something you can stop.

The public [gives you the message that it's in your head]. I wouldn't say that the doctor's office does. The doctor's office I go to is really great. It's all women, and I feel like they all know. They've seen enough patients come through that they know. But as far as other women in the public and other people, they think it's all in your head, and they don't understand why you're so sick. Because they weren't sick, they think you're just weak.

Finally, as previously discussed, the necessity of one's doctor verifying the illness as HG to family members was reiterated throughout the interviews. For example:

I think they [doctors] should have some kind of an information guide for people to give to their families because they don't understand either. I felt like my family thought that I was just almost pretending or I couldn't take a simple illness that most people get through without any problems, and they didn't realize the extent that I had the problem. With the first pregnancy, they thought it was all psychological. But then in this fourth pregnancy, people were much better about it because the doctor came right out and said, "This is physical, it is like having the flu around the clock." He explained it, and then it was like all of a sudden, well totally it's not her fault now.

### Limitations of the Study

This study has a number of characteristics that may affect the generalizability of the results. These include (a) demand characteristics, (b) retrospective design, (c) measurement error, and (d) additional general limitations.

#### Demand Characteristics

One limitation is the demand characteristic of research in which respondents may feel obligated to participate. Or, in their effort to give socially desirable responses, respondents tend to modify their answers so as not to appear deviant (Henerson, Morris, & Fitz-Gibbon, 1987). Not only do respondents tend to provide responses that they think the researcher would like to hear, they may also downplay, for instance, a relatively poor performance (Conway, 1990) or negative feelings (Breetvelt & VanDam, 1991) in order to protect self-esteem. For example, with regard to quality of life issues, Breetwelt and VanDam noted that cancer patients have been found to report a lesser degree of negative feelings despite investigators' suspicions of higher degrees of negative feeling. These authors contended that the phenomenon of underreporting psychosocial distress occurs more frequently in self-report measures and applies to patient groups other than cancer patients. Thus, the unique personality and demand characteristics that might influence the respondents' willingness to self-select themselves to participate or the ways in which individual characteristics affect response style cannot be fully known.

### Retrospective Design

A second limitation is that the retrospective design elicited patients' reconstructed perceptions of their HG experience and the patient-doctor relationship rather than observing the actual behavioral and communication exchange of doctor-patient pairs. Doctor beliefs were defined as patients' perceptions and should not be regarded as actual doctor beliefs. Although patients' recall may be less than accurate, patients' perceptions (vs. observational studies of verbal and nonverbal patient-doctor interaction) are considered important because they may affect their own future behavior and outcomes (Brody et al., 1989). They are also considered a legitimate outcome measure of health care quality (Ross et al., 1995).

In addition, the retrospective design calls into question the accuracy of the respondents' recollection of their attitudes, beliefs, and feelings of the past event. There is, however, some evidence in the memory literature to suggest that autobiographical memories of remembered real events (vs. childhood talked-about events, for example) are more clear and intense (McGinnis & Roberts, 1996), and rare events (as opposed to common, everyday events) occurring six years earlier can be recalled well (White, 1989). In related research, chronic-pain patients were found to have greater recall of their pain, as compared to nonpain, memories (Wright & Morley, 1995), and women's retrospective accounts of their reactions to their miscarriage events have been found not to be easily forgotten and can be recalled in considerable detail (Conway, 1995). Frank (1995) posited that "people's memories of illness are often remarkable in their precision and duration" (p. 59).

Moreover, the qualitative comments demonstrated that memory was not a significant problem for these respondents. The overwhelming number of comments pertaining to respondents' recollection of their HG experience reflected statements such as "I will never forget it," "It is very fresh in my mind," and "It was such a traumatic experience; it was seriously traumatic . . . that is probably why it is so fresh [in my mind]. . . . I could sit here and cry like it was yesterday, I don't think I will ever forget it."

Although many were able to recall specific sights, smells, sounds, words, and conversations, a few comments about memory difficulties occurred when respondents attempted to recall specific words and sentences in their encounters with their doctors (e.g., "I can't remember exactly what he said."). All respondents were able to describe the overall demeanor of the doctors and the atmosphere of the encounters, however. Thus, it may be that this rare, physically and emotionally significant event of being ill as well as hospitalized with HG, with its known risks to mother and baby, was reconstructed with some reasonable degree of accuracy.

Still, the retrospective design is limited in that respondents' hindsight memory may be biased by their knowledge of subsequent events and their current attitudes (Conway, 1990). For example, if a patient's experience with her doctor during the HG experience was quite positive, but she had since encountered interpersonal difficulties with the doctor (and vice versa), her reported recollection of the HG event may have been biased to include a combination of her past and present attitudes and feelings.



The decision to use a retrospective versus a prospective design was based on the following considerations. First, a prospective design would not yield a sufficient sample size due to the statistically low rate of occurrence of HG and the time and resource constraints of this study.

Second, responses may have differed depending on the social context of a study (Like & Zyzanski, 1987). There is empirical evidence suggesting that healthier patients tend to be more satisfied with their physicians than less healthy patients (Ong et al., 1995). Thus, being in the midst of an illness might distort perceptions because ill patients may be less responsive or more depressed and irritable. For the purpose of this study, it was hoped that the present-day context of being HG-free (e.g., healthy as opposed to ill) and the outpatient (vs. inpatient) environment would allow the recollection of the most salient positive and negative memories. One respondent's remarks demonstrate the benefit of using a retrospective design for this study. She described being upset that she had been asked to participate in another HG study at the time she was hospitalized. She noted feeling "too sick" to talk about it then, explaining that she had a better perspective now (e.g., well after the pregnancy and delivery experience). She stated,

I got kind of upset she [researcher] was there because I was so sick. I didn't want to even talk about it. I didn't even want anything to do with that [study]. But now that I can, you know, it's over with, I don't mind talking about it. [Being in the hospital] is the wrong time. It's like, "Get away from me." It's not a good idea to do that, to interview somebody that's going through it at the time. It's best to ask after they have gone through it because it's emotionally tearing you up.

Conversely, it is also a possibility that women who experience pregnancy complications but deliver a healthy baby may minimize the effect of the antenatal stress and uncertainty when reflecting on the experience (Zuskar, 1987).

Third, the demand characteristic of this type of health care research can be more prevalent in a prospective design. Although issues of irritability and depression may distort an ill patient's responses toward the negative, many people still desire to be "the good patient" and find it particularly difficult to admit negative or ambivalent feelings about health care professionals who are actively attempting to ease pain and suffering. In particular, Gilligan's (1982) analysis of women's psychological development showed how socialization into gender roles often leads women to behave in the "good patient" role. In addition, the stress of hospitalization (MacMullen et al., 1992) combined with the physical discomfort of HG may cause patients to feel particularly vulnerable and dependent; patients may not have the physical or emotional energy needed to express negative or ambivalent feelings about their doctors. Moreover, despite the confidentiality of a research study, patients in the midst of their illness may not feel completely confident in expressing the range of their feelings for fear of upsetting their doctors or fear of retaliation by hospitals' or physicians' office staff.

### Measurement Error

Despite the lack of correspondence between quantitative and qualitative findings, it is the researcher's contention that the study hypotheses were appropriate. Measurement error, especially with regard to item construction, is an inevitable limitation in any study. As a result of this effort, revision of the HG Questionnaire is

warranted. For example, as previously discussed, low reliability coefficients for patients' perceptions of their doctors' beliefs (as well as patients' own beliefs) on the subscale Causal I: General raises concerns regarding the internal consistency of the entire scale, despite an acceptable overall reliability coefficient of .7519.

Another example is that although qualitative comments showed that the majority of participants described numerous ways in which HG placed strain on the family, some respondents reported lower scores on this Impact item for two possible reasons. In response to Item 20, "Having HG created a strain on my family relationships," one respondent asked, "Is that a bad thing?" Thus, "family strain" was interpreted as something that might portray her family in a negative light. Another woman described numerous ways HG interfered with family functioning, yet denied HG as placing a strain on family relationships because the family was generally "supportive." Thus, in addition to demand characteristics, perhaps the wording of this item was misinterpreted by some as "family conflict" as opposed to the intention of the strain and stress that illness commonly places on families.

#### **Additional General Limitations**

Interpretation of the results of this study is limited by several other considerations. Findings are applicable to the population of HG patients (and their respective physicians) who have encountered at least one inpatient hospitalization in a regional perinatal medical hospital or similar high-risk obstetric unit. Caution must be used when generalizing to patients outside of western Michigan as sociodemographic

characteristics of both patients and their doctors may differ significantly from the sample used in this study.

Further, this study, like all telephone surveys, was subject to the potential effects of coverage error (Lavrakas, 1993). That is, a proportion of potential respondents were unable to be reached by telephone, possibly due to the reality that citizens without telephones, as a group, have lower incomes than people with telephones. Thus, the findings of this study may be the result of "somewhat higher levels of income and income-related behaviors among its respondents than exists in the overall population" (Lavrakas, 1993, p. 3). Nonetheless, although there is evidence for class differences in women's relationship to the medical system (Ehrenreich & English, 1973; Murrell, Smith, Gill, & Oxley, 1996), and race discrimination in the patient-doctor relationship (Ehrenreich & English, 1973; Todd, 1989), the data in this study suggest that patients' beliefs about and their experience of living with HG remained quite consistent for this patient population.

Last, because the anonymity of the physicians represented in this study was maintained, it is unknown whether the Satisfaction outcome measure represented 96 individual physicians or whether some physicians provided care to more than one respondent. It cannot be determined from the data whether the women in this study gravitated toward a few physicians with good reputations for providing obstetric and/or HG care, possibly skewing the results in a positive direction.

## **Implications**

### **Practice Implications**

The findings of this study have unique implications for HG patients and their physicians. Women with HG typically present as quite ill and often require frequent encounters with their physicians, especially in the early, acute phase of the illness. Moreover, ambivalence about the timing of or one's desire for pregnancy and parenthood during the first two trimesters of pregnancy is a common developmental stage for pregnant women. This expected ambivalence of early pregnancy is often compounded for HG patients due to the severity and duration of the nausea and vomiting. Physicians who understand the psychosocial aspects of high-risk pregnancy are better equipped to provide the much-needed education and support to their patients.

Moreover, physicians' understanding of these dynamics as common responses to high-risk pregnancy and HG, and not necessarily indicative of women's rejection of the fetus, will aid them in avoiding the trap of presuming a psychogenic etiology. Physicians will thereby be freed up to sensitively educate HG patients about the benefits of referral for professional counseling and/or lay support groups, viewing these referrals as routine in most cases of severe illness and high-risk pregnancy in particular, rather than singling out HG patients because of a presumed psychological component. As the data in this and other studies (Waitzkin, 1991) have shown, problems arising from and affected by illness must be addressed as they are deemed important to patients.

In addition, physicians' attention to the psychosocial aspects of HG and the importance of the psychosocial support provided by physicians becomes even more

imperative as recent advancements in medical technology have shifted the care of HG patients from inpatient hospitalization to home health care (Cowen, 1996; Naef et al., 1995). For some HG patients, arrangements for home IV therapy can be made from the physician's office and/or the emergency room, without the patient ever being hospitalized. Despite the benefits of home health care services, patients who are not hospitalized will not receive the additional psychosocial support services provided by hospital nurses and social workers specifically trained in high-risk obstetric care. They also will be less likely to come into contact with other HG patients. It is imperative that physicians and their office staff be aware of, and refer homebound patients to, local professional and lay support programs.

Furthermore, physicians' understanding of and communication with patients and their families that HG is "real" and that the woman is "ill" becomes more imperative in light of home health care services. As the data in this study showed, hospitalization often validated the seriousness of the illness to patients and their families. To mobilize patients' social support, physicians and their office staffs need to take a proactive role in explaining that it is not the severity of HG patients' symptoms that has changed, but that invasive medical interventions can now be provided in the home.

Also, the data offer information about physician behaviors and characteristics that patients view as helpful. Understanding the factors that contribute to patients' satisfaction with the care received from their doctors can lead to the development of more effective educational and clinical intervention strategies. In addition to biomedical competence, developing innovative medical education programs that emphasize

attitudes and values about the patient-physician relationship (Wolf, Ingelfinger, & Schmitz, 1995), reexamine stereotypical attitudes about women and health (Phillips, 1995), train doctors to evaluate their own psychological responses to patients (Keller & Carroll, 1994), and teach humanistic interpersonal and communication skills (Branch & Malik, 1993; Hendrie & Lloyd, 1990; Novack, 1987; Spiro, 1992) are warranted. Moreover, emphasizing patient satisfaction in medical education is important as a major outcome measure of psychosocial training programs in medical education is patient satisfaction (Smith et al., 1995). Similarly, because of their frequent interaction with patients and their role as "gatekeepers" of medical care, office nursing and secretarial staff would benefit from educational programs aimed at developing and enhancing these skills.

In addition, the knowledge gained from this study may assist social workers in health care with their practice with patients, multidisciplinary team members, and health care organizations. Understanding women's experiences of HG can help social workers to intervene more effectively with patients and their families, addressing issues related to the psychosocial adaptation to the illness. Social workers can assume leadership in developing both inpatient and outpatient support groups for HG patients. They can also impact patient care by effecting change within their organizations and among other health care providers. In their role as liaison between patients and health care providers, social workers can use this knowledge of patient satisfaction to "help patients develop realistic and positive expectations of their care, they can help patients communicate their expectations to providers, and they can encourage health providers

to recognize and meet those expectations" (Hsieh & Kagle, 1991, p. 289). Social workers can continue to participate in the psychosocial aspects of physician education (Hunsdon & Clark, 1984; Zayas & Dyche, 1992) and social work education in both clinical and academic settings.

Finally, the results of this study can assist social workers, along with their medical and nursing colleagues, in reconsidering their own ideologies about HG patients. A reevaluation of the ways in which a health care professional's interaction with HG patients may, in and of itself, be a psychosocial stressor that contributes to exacerbating symptoms and impeding recovery will be valuable in promoting better patient care (Munch, 1991). Moreover, the results of this study can help health care providers spanning all disciplines to challenge erroneous assumptions that permeate the literature about women patients and HG patients in particular.

### **Policy Implications**

Policy implications resulting from this study that examined aspects of the patient-doctor relationship and patient satisfaction are apparent. In light of diminished health care financing, it would be beneficial for physicians and insurance companies to develop and/or review established medical protocols for HG patients. There is some evidence in this study to suggest that delayed diagnosis and treatment of HG occurs. Whether this occurs as a result of the inherent difficulty in making the differential diagnosis between NVP and HG or physicians' stereotypical beliefs about women with HG is not clear.



What is clear, however, is that delayed diagnosis and treatment affects patient satisfaction; it also can contribute to the exacerbation of HG symptoms, thereby necessitating expensive invasive home health care and/or hospital services. In addition, insurance providers might benefit from understanding that unnecessary formal psychiatric consultations for HG patients tend to reduce patient satisfaction and may impede patients' recovery, adding to health care costs, whereas integrating routine provision of inpatient and outpatient mental health benefits into primary care for all patients can be cost effective and improve clinical outcomes (Hoffman, Maraldo, Coons, & Johnson, 1997).

In addition, the results of this study demonstrated the importance of the patient-doctor relationship and the continuity of care. In particular, the benefits of this relationship characterized by mutuality and compassion was appreciated by patients. However, managed care poses some threats to this relationship. Despite managed care's movement for quality measurement and improvement within health delivery systems, including measures of patient satisfaction, there remain problems. Carlson (1997) concluded: "The current system of managed care also poses some threats to efforts to improve the quality of women's primary care. Chief among these is erosion of the doctor-patient relationship through productivity pressures [and] disincentives for maintenance of continuity" (p. 359).

Moreover, time constraints placed on physicians can prohibit the provision of patient-centered care. Hoffman et al. (1997) stated:

Such an approach, however, requires enough time for thoughtful and attentive listening, something not provided in volume-driven practices that measure

clinician productivity by quantity of encounters rather than quality of encounters. Time-limited encounters force patients and their providers into reductionist modes of thinking in which decontextualized problems require immediate (often inappropriate) responses and, simultaneously, mitigate against "relationship-centered care."

Finally, implications for national health care policy and the allocation of research dollars to women's health issues exist. Significant advances in the organization and focus of women's health issues have occurred since the National Institutes of Health established the Office of Research on Women's Health in 1990 (Pinn, 1994). However, women's health care continues to face a number of problems due to the relative lack of biomedical research on conditions affecting women, such as the lack of any effective treatment for the more than one million women who endure nausea and vomiting of early pregnancy (Longo, 1997).

### Directions for Future Research

There is a multiplicity of proposed causes, yet a scarcity of research on the topic of HG. This is not unlike other female medical conditions that, until recently, have not been researched. More women-centered research is needed, especially with regard to women's health care. Oakley (1993a), an exemplary scholar on women's health issues, called for research methods that address the important meanings of health to women and urged a feminist methodology that recognizes women's health is bound up with their everyday lives. Similarly, King (1992) stated, "Too often, women's medical care as viewed through the cultural lens of gender differences becomes a contradiction between the 'reality' of medicine and the woman's 'own inner sense of the way things are'" (p. 9).

With regard to HG research, comparing these results to a sample of outpatients (e.g., women treated and released from the emergency department and/or receiving home health care services) would provide further information regarding any similarities or differences between inpatients' and outpatients' experiences. Incorporating a measure of patients' expectations for HG treatment may be useful as other literature has shown that patients' expectations are important determinants of patient satisfaction (Hsieh & Kagle, 1991; Kenny, 1995; Like & Zyzanski, 1987).

In addition, investigating patients' and doctors' perceptions of their relationship and how their perceptions relate to patient satisfaction using matched patient-physician pairs may prove beneficial (Anderson & Zimmerman, 1993). Moreover, research investigating the personal reactions of physicians and other health care providers has been largely ignored in the literature (Hardin & Hailey, 1993). An examination of attitudes and beliefs about HG patients by their health care providers would contribute to identifying, understanding, and modifying, if necessary, current beliefs that influence health care practice. Further, examining the role of patient stress resulting from health care professionals' stereotypical attitudes and/or nonhumanistic behaviors may prove beneficial.

Patient satisfaction should be included but not the only outcome measure of the patient-physician relationship as some patients may be satisfied with less than optimal health care or outcomes because of the humanistic qualities of their doctors (Kaplan et al., 1989). Therefore, research exploring the association between the patient-doctor relationship and maternal and infant medical and psychosocial outcomes is warranted.

Next, feminist scholars are advocating for more cultural diversity within feminist research (Landrine, Klonoff, & Brown-Collins, 1992). Anderson (1993) asserted that we must acknowledge the "complex, multiple, and contradictory identities and realities that shape our collective experience" (p. 51). It would be beneficial to explore HG patients' experiences of the patient-physician relationship in terms of race and class.

For example, one respondent noted that although she and her doctor were of the same racial minority, she attributed her unsatisfactory care to her being on the state insurance program, Medicaid. She asserted that some people of her racial group think poor care is a "race issue"; in her case, she believed her lower social class was the issue. This is consistent with others who advocate addressing the "broader question of how social inequities resulting from divisions based on race, gender, and class may produce a general state of psychological distress that can, in turn, affect people's hope (or hopelessness) and thus their health behaviors" (Krieger et al., 1993, p. 109). Unfortunately, little has been documented in the gender and health literature regarding how race and class enter into women's differential treatment with regard to physicians' diagnosing and treatment practices. Women of color are challenging feminist scholarship to rethink how gender intersects with other inequalities (Baca-Zinn & Dill, 1994; hooks, 1984).

Next, information gained from the women in this study suggests that extending the unit of analysis beyond the patient-doctor relationship, thereby including relevant health care professionals and patients' social support network, may more fully encompass women's health care experiences with HG.

Finally, there are difficulties inherent in conducting social science research due to the continuously changing variables and the complexity of the interplay between human subjects and their environment (Raphael, 1994). In particular, the complex nature of the patient-physician relationship combined with the unlimited variables that may, at any given time, contribute to patients' reports of satisfaction with their medical care creates unique issues for researchers. Combining qualitative and quantitative approaches in the field of patient satisfaction may prove most beneficial as embracing "different theories, methodologies, levels of focus (macro or micro), and kinds of data and data gathering . . . will reduce inevitable bias by rotating the perspective on the system under investigation" (Heineman, 1981, p. 391). Moreover, remaining open to patterns other than linear relationships is necessary in the study of complex psychosocial and interpersonal phenomena.

### Conclusion

The socioemotional aspects of the patient-physician relationship are of known import for many patients, taking on even greater significance in the lives of pregnant women. Specifically, the study has described women's lived experiences with HG and their perceptions of the unique aspects of the patient-doctor relationship contributing to patient satisfaction by giving voice to the 96 women in this study who had experienced the pregnancy complication of HG. The findings of this study support the claim made by previous researchers that socioemotional aspects of physicians' care are valued by patients.

Moreover, respondents in this study did not perceive, for the most part, their own doctors interacting with them based on outmoded and gender-biased theories and assumptions of human development and HG. They did, however, encounter negative interactions with other physicians and health care professionals. Whether these unsatisfactory relationships were the result of gender bias and false assumptions about women, and women with HG in particular, or from doctors' own sense of frustration and feelings of helplessness because there is no known biological etiology, treatment, or cure for HG, cannot be determined from these results. However, the findings do support the notion that patients' perceptions of their physicians' attitudes and behaviors affect reported patient satisfaction; they are also a form of social support that can affect patients' emotional and possibly physical status.

Even though physicians and other health care professionals today may not consciously maintain the strict psychoanalytic view that HG is a symbolic rejection of the fetus, motherhood, and femininity, the notion of psychogenesis for this diagnostic group is entrenched in the socialization process of doctors and patients in Western society. HG continues to raise suspicion about the primacy of psychological factors, even among the most humanistic physicians, hence the finding suggesting that physicians tend to delay treatment and/or demonstrate more empathy during subsequent HG pregnancies as compared to patients' first HG pregnancy.

In addition, the discourse in current diagnostic manuals and medical textbooks demonstrates that physicians are still being trained in a model of this illness that does not comport with patients' experiences. The International Classification of Diseases.

Ninth Revision, Clinical Modification (Practice Management Information Corporation, 1997), which classifies diagnostic categories for hospitalized patients, includes a subcode (306.4) for HG labeled "psychogenic." The Merck Manual of Diagnosis and Therapy (Berkow & Fletcher, 1992) emphasizes the psychological component while acknowledging the physiological seriousness, stating, "Psychologic factors are prominent in this syndrome but do not lessen the danger."

The characterization of HG has certainly improved over the years. The fifth edition of Obstetrics (1923) described "neurotic vomiting" as the cause of the vast majority of HG patients. DeLee and Greenhill (1943) stated, "Hyperemesis is not rare in hysterical women, and it may be a pure neurosis. It may also be a psychologic manifestation. If the pregnancy is abhorrent or fearful to the woman, she may, consciously or subconsciously, as a protest go on a 'hunger strike,' and vomit" (p. 350). In contrast, modern medical texts tend to use more caution in their descriptors (e.g., use of the word "some" vs. "most"). For example, "For some women with hyperemesis gravidarum there is a very significant psychologic component" (Brenner & Goodwin, 1994, p. 193).

Nevertheless, these texts neglect to describe the psychosocial effects created by HG, leaving readers to conclude only that psychological and stress-related factors are the predominant components contributing to the expression of this illness. Still another example is the 19th edition of Williams Obstetrics (Cunningham, MacDonald, Leveno, Gant, & Gilstrap, 1993), which states, "In many instances, social and psychological factors contribute to the illness. . . . The woman usually improves remarkably while

hospitalized, only to relapse after discharge" (p. 1146). However, the data in this dissertation study suggested consideration of alternative explanations for relapses (e.g., delayed diagnosis and treatment, lack of a known effective treatment, patients' lack of rest due to others' invalidation of the sick role). In sum, in their landmark study of gender bias and women's health care, Lennane and Lennane (1973) concluded, "The belief in psychogenesis, once reached, is remarkably persistent" (p. 291).

Clearly, the sharp distinction purposefully created in this study between the "biological" and the "psychological" etiologies of HG is an artificial one. If the problem of gender bias in our society and health care system is ever resolved, making the distinction will become less important as we acknowledge a biopsychosocial model of health and illness--the interplay among the body, the mind, and the environment--without presuming a psychological etiology of HG based on erroneous assumptions. Moreover, the data in this study demonstrated that women acknowledge the interrelated role of biological, psychological, and environmental stress factors. An assessment of both physical and psychosocial events should occur in most cases of illness. The danger occurs when female patients with certain disease/illness entities are singled out based on stereotypical assumptions and attitudes. Moreover, there is the potential for overlooking quite serious conditions, both biological and psychological. Erroneous beliefs and assumptions about sex-roles may lead to misdiagnosis and ineffective or even dangerous treatment (Council on Ethical and Judicial Affairs, 1991).

Furthermore, it is not surprising that previous studies have reported a relationship between psychological factors/psychosocial stressors and HG. The



qualitative data in this study also demonstrated that the two coexist. However, unlike previous studies, the temporal relationship of psychological factors/stress became more clear in this study. The qualitative data suggested that although psychological factors/stress may be primary contributors to HG, it is equally plausible (and the experience of the majority of women in this study) that HG caused the stress and psychological distress. Previous studies have overlooked this equally logical conclusion. Reframing the question about the temporal relationship between stress and HG is important in altering the misperception that HG is primarily a psychogenic illness. As the data in this study showed, this misperception and its concomitant issues (e.g., not being believed; lack of doctor action) were major sources of patient dissatisfaction with the care received from their doctors in the treatment of HG.

In conclusion, this study has documented that strong and positive relationships between women and their doctors exist for HG patients. This study also supports the notion that physicians are not only prescribers of therapy but can be therapeutic themselves (Epstein et al., 1993). Combining quantitative and qualitative approaches in research regarding HG, the patient-physician relationship and patient satisfaction adds depth to data that neither can accomplish independently. Giving voice to women's experiences and perceptions as patients, and patients with HG in particular, has the potential to produce knowledge useful to both medicine and the social sciences-- knowledge that has previously gone undetected.

## APPENDICES

## **APPENDIX A**

### **CONSENT FORM**

## CONSENT FORM

You agree to participate in a research study about women who have had hyperemesis (severe nausea and vomiting of pregnancy), and have been hospitalized for this condition at \_\_\_\_\_. There will be approximately 80-100 women participating in the study. This study is being conducted by, Shari Munch, M.S.W., a social worker at \_\_\_\_\_ Hospital and doctoral candidate in the School of Social Work at Michigan State University.

There is no risk involved for you in answering these questions. While there is no direct benefit to you, the answers obtained may help in the understanding of this condition and others who might experience this.

By agreeing to participate in the study, you will be asked to answer questions about your current or most recent pregnancy in which you had hyperemesis. You will be contacted by telephone for one interview that is estimated to last approximately 20-30 minutes. You will receive no compensation for your participation in this study.

You can choose not to participate, and can change your mind and decide not to participate at any time without fear or prejudice. In addition, you can refuse to answer any question that you are asked. This will not affect any health care that you receive now or in the future.

The information you provide will be known to both Shari Munch and her research assistant. Your name will not appear on the questionnaire and you will be assigned a code number. You will not be identified by name at any time in this project and all information that might lead to your identification will be disguised. Confidentiality will be protected to the extent permitted by law.

You are free to ask questions of Shari Munch (ph. xxx) or her advisor, Dr. Rena Harold at Michigan State University (ph. xxx). If you have questions regarding your rights as a patient, you may call \_\_\_\_\_ Hospital's Human Rights Representative, \_\_\_\_\_ (ph. xxx).

You will be given a copy of this signed consent form, and your signature indicates that you have volunteered to participate in this study having read the information provided. You will receive a summary of the project results.

\_\_\_\_\_  
Name of Participant in Print/Signature

Date \_\_\_\_\_

\_\_\_\_\_  
Name of Witness in Print/Signature

Date \_\_\_\_\_

\_\_\_\_\_  
Shari L. Munch/Signature

Date \_\_\_\_\_

## **APPENDIX B**

### **COVER LETTER**

Date

Dear

Enclosed are two copies of the same consent form for the research study about hyperemesis (severe nausea and vomiting during pregnancy) that we spoke about on the telephone. Although you have already agreed to participate in this study, this is a form that I need to keep on file. Again, I thank-you in advance for agreeing to participate in this research study.

After you and a witness have printed and signed your name (include date) on both forms, please **mail one consent form back to me in the self-addressed stamped envelope**. The other form is yours to keep for your records.

As we agreed on the phone, I will call you on \_\_\_\_\_ at \_\_\_\_\_.

Sincerely,

Marsha Lampen  
Research Assistant, Michigan State University  
ph. xxx

Shari Munch  
Primary Researcher  
\_\_\_\_\_ Hospital/Michigan State University  
ph. xxx

## **APPENDIX C**

### **HYPEREMESIS QUESTIONNAIRE**

## HYPEREMESIS QUESTIONNAIRE

Date: day \_\_\_\_ mo \_\_\_\_ yr \_\_\_\_

1. Respondent I.D. Number \_\_\_\_

2. Hospital Status: \_\_\_\_ (1=Inpatient)

3. HIG Pregnancy of Interest: \_\_\_\_ Month \_\_\_\_ Year (date of most recent admission)

Researcher: \_\_\_\_

Tape Recorded Open-Ended Questions \_\_\_\_ Yes \_\_\_\_ No

### General Instructions

I am going to ask you some questions about your most recent pregnancy in which you were diagnosed with hyperemesis. So, the pregnancy we will be talking about is the one when you were hospitalized at \_\_\_\_ on \_\_\_\_\_. When you are answering the questions think only about the time period during this pregnancy when you had hyperemesis -- that is, the times that you were either in the hospital and/or at home and had hyperemesis.

### Personal Background

I'd like to begin by asking a few questions about your background. Please answer the questions only for the time period during this pregnancy/your \_\_\_\_ pregnancy when you had hyperemesis. (For example, if you were single when had hyperemesis, but you are married now --- answer single.)

4. Age in Years \_\_\_\_ (verify with respondent)

5. Marital Status (circle one):

- 1 Never Married
- 2 Married
- 3 Separated
- 4 Divorced
- 5 Widowed
- 6 Living with Partner
- 7 Other -- specify

6. Ethnic or Racial Identification:

- 1 Asian or Pacific Islander
- 2 Black or African American
- 3 Hispanic
- 4 Native American
- 5 White
- 6 Other -- specify



7. Highest Level of Education:

- 1 No high school diploma  
 2 High school diploma or GED  
 3 Some college, no degree  
 4 Technical or Junior college degree  
 5 College degree  
 6 Graduate degree

8. Employment (circle one):

- 1 Full-time  
 2 Part-time  
 3 Homemaker, retired or otherwise not seeking work  
 4 Unemployed and seeking work

9. Total Household Income Level Per Year (circle one):

- 1 Less than \$10,000  
 2 \$10,000 to \$29,999  
 3 \$30,000 to \$49,999  
 4 \$50,000 to \$69,999  
 5 More than \$69,999

Current HG Pregnancy Only

10. How many weeks along are you? \_\_\_\_

11. What is your due date? \_\_\_\_

Prior HG Pregnancy Only

12. Fetal Demise: (1=Yes; 2=No) \_\_\_\_ (Explain if appropriate: \_\_\_\_\_)  
 (If Yes, ask only #15 in this section)

13. What day was your baby born? \_\_\_\_

14. Is your baby a boy or girl (1= female; 2= male): \_\_\_\_

15. How far along were you when you delivered your baby? \_\_\_\_ Weeks

16. How much did your baby weigh when it was born? Pounds \_\_\_\_ Ounces \_\_\_\_

## Hyperemesis Information

17. Number of hospital admissions: \_\_\_\_\_ (verify with respondent)

18. Number of emergency department visits: \_\_\_\_\_

19. Number of days hospitalized for each admission:

First Admission \_\_\_\_\_ Days

Second Admission \_\_\_\_\_ Days

Third Admission \_\_\_\_\_ Days

Fourth Admission \_\_\_\_\_ Days

Fifth Admission \_\_\_\_\_ Days

20. ICD-9 Diagnosis: \_\_\_\_\_ (1=mild/64303; 2=severe/64313)

Now I would like to ask you a few questions about your experience with hyperemesis. Again, answer the questions only for the time period during this pregnancy/your \_\_\_\_\_ pregnancy when you had hyperemesis.

21. Were you transferred to \_\_\_\_\_ Hospital from another hospital? (1=Yes; 2=No) \_\_\_\_\_

22. Which of the following did you receive in the hospital? (Please answer yes/no after each item that I read on the list)

1. Special Diet

2. Nausea Medication

3. IV Fluid Therapy (an IV that goes into your arm)

4. Nasogastric Tube (NG tube) (a feeding tube that goes down your nose into your stomach)

5. TPN (an IV that goes into your neck) [Total Parenteral Nutrition]

6. None

23. Were you discharged to your home with any of the following services? (Please answer yes/no after each item that I read on the list)

1. Special Diet

2. Nausea Medication

3. IV Fluid Therapy (an IV that goes into your arm)

4. Nasogastric Tube (NG tube) (a tube that goes down your nose into your stomach)

5. TPN (an IV that goes into your neck)

6. Visiting Nurse

7. None

24. How many times have you been pregnant [total]? \_\_\_\_\_ (Please include any miscarriages or abortions you may have had)

25. Which pregnancy for you was this hyperemesis pregnancy that we are talking about? \_\_\_\_\_

26. In which of your other pregnancies were you diagnosed with hyperemesis?

- ☐ 1 Not Applicable  
☐ 2 None  
☐ 3 First Pregnancy  
☐ 4 Second Pregnancy  
☐ 5 Third Pregnancy  
☐ 6 Fourth Pregnancy  
☐ 7 Other Pregnancy -- specify \_\_\_\_\_

#### Physician Information

Now I'd like to ask you some background information about your doctor. Do not tell me your doctor's name. But in your own head, think only about the doctor who took care of you the most for your hyperemesis. If you were sick with hyperemesis for three weeks, think about the doctor who took care of you during those three weeks. Or, if you were sick with hyperemesis for four months, think about the doctor who took care of you during those four months of your pregnancy. The doctor you are thinking about may or may not be the one who saw you in the hospital. I want you to think about the doctor who took care of you the most (either in the hospital, at home or both) for your hyperemesis. Do you have any questions?

27. Physician's Gender (1= female; 2= male) \_\_\_\_\_

28. Physician's Ethnic or Racial Identification (circle one):

- ☐ 1 Asian or Pacific Islander  
☐ 2 Black or African American  
☐ 3 Hispanic  
☐ 4 Native American  
☐ 5 White  
☐ 6 Other -- specify \_\_\_\_\_

29. What was your doctor's specialty?

- ☐ 1 Family Practice  
☐ 2 Obstetrician-Gynecologist  
☐ 3 Perinatologist (Maternal-Fetal Medicine)  
☐ 4 Other: please specify \_\_\_\_\_  
☐ 5 Not Sure

30. At the time, how long had she/he been your doctor?

- ☐ 1 One week or less  
☐ 2 Two-four weeks  
☐ 3 Two-six months  
☐ 4 Seven-eleven months  
☐ 5 One-two years  
☐ 6 More than 2 years

**Beliefs about the Hyperemesis Experience**

Instruction #1: In the next set of questions I am interested in understanding what you believed at the time you had hyperemesis. After I read each statement, tell me how strongly you agree or disagree with the statement. This is not a test of what you know. There are no right or wrong answers to any of these questions. I am interested in your opinion or your best impression about each statement. Your choices are Strongly Disagree, Disagree, Agree and Strongly Agree. Please take a moment to jot these down on a piece of paper.

Instruction #2: I've just asked you questions about your beliefs at the time you had hyperemesis. Now I want you to think back to what you thought your doctor believed at the time she/he was treating you for hyperemesis. That is, what did you think your doctor was thinking? We are still talking about the same doctor you were thinking about earlier. I realize that it is difficult for any of us to know what someone else is thinking. But, what was your impression of your doctor's beliefs and attitudes at the time you were being treated for hyperemesis? Again, there are no right or wrong answers.

What You Believed                      What You Thought  
Your Doctor Believed

SD    D    A    SA                      SD    D    A    SA

Causal Explanations

I. General:

These first few questions are about hyperemesis in general, not your specific situation.

- |    |                                                                                                                                                                                                                                                                                                                     |   |   |   |   |   |   |   |   |
|----|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---|---|---|---|---|---|---|---|
| 1. | In general, the cause of hyperemesis tends to be mostly biological/medical.<br>(e.g., physical cause such as hormones) [physiological]<br><i>In general, my doctor believed that the cause of hyperemesis tends to be mostly biological/medical.</i> (e.g., physical cause such as hormones)                        | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| 2. | In general, hyperemesis is mostly caused by stress. [environmental]<br>(e.g., personal problems: work problems, money problems, family problems)<br><i>In general, my doctor believed that hyperemesis is mostly caused by stress.</i><br>(e.g., personal problems: work problems, money problems, family problems) | 4 | 3 | 2 | 1 | 4 | 3 | 2 | 1 |
| 3. | In general, the cause of hyperemesis tends to be mostly psychological.<br>(e.g., anxiety, depression, mental illness) [psychological]<br><i>In general, my doctor believed that the cause of hyperemesis tends to be mostly psychological.</i> (e.g., anxiety, depression, mental illness)                          | 4 | 3 | 2 | 1 | 4 | 3 | 2 | 1 |

|                                                                                                                                                                                                                                                 | <u>What You Believed</u> |   |   |    | <u>What You Thought<br/>Your Doctor Believed</u> |   |   |    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|---|---|----|--------------------------------------------------|---|---|----|
|                                                                                                                                                                                                                                                 | SD                       | D | A | SA | SD                                               | D | A | SA |
| 4. In general, hyperemesis is mostly hereditary. [genetic]<br>(e.g., genetic; passed down from your parents)<br><i>In general, my doctor believed that hyperemesis is mostly hereditary.<br/>(e.g., genetic; passed down from your parents)</i> | 1                        | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| 5. I believed that hyperemesis is caused by both physical and<br>psychological factors.<br><i>My doctor believed that hyperemesis is caused by both physical and<br/>psychological factors.</i>                                                 | 1                        | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| 6. The cause of hyperemesis is not known.<br><i>My doctor believed that the cause of hyperemesis is not known.</i>                                                                                                                              | 1                        | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| II. Personal Attributions :                                                                                                                                                                                                                     |                          |   |   |    |                                                  |   |   |    |
| The rest of the questions are about your <u>specific experience</u> with hyperemesis.                                                                                                                                                           |                          |   |   |    |                                                  |   |   |    |
| 7. I got hyperemesis because I am a weak and sickly person.<br><i>My doctor believed that I got hyperemesis because I am a weak and<br/>sickly person.</i>                                                                                      | 4                        | 3 | 2 | 1  | 4                                                | 3 | 2 | 1  |
| 8. I could have prevented getting hyperemesis.<br><i>My doctor believed that I could have prevented getting hyperemesis.</i>                                                                                                                    | 4                        | 3 | 2 | 1  | 4                                                | 3 | 2 | 1  |
| 9. I got hyperemesis because I didn't cope well with my personal problems.<br><i>My doctor believed that I got hyperemesis because I didn't cope well<br/>with my personal problems.</i>                                                        | 4                        | 3 | 2 | 1  | 4                                                | 3 | 2 | 1  |
| 10. My hyperemesis was "all in my head."<br><i>My doctor believed that my hyperemesis was "all in my head."</i>                                                                                                                                 | 4                        | 3 | 2 | 1  | 4                                                | 3 | 2 | 1  |

|                                            |                                                                                                                                                                                                                | <u>What You Believed</u>     |   |   |    | <u>What You Thought<br/>Your Doctor Believed</u> |   |   |    |
|--------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------|---|---|----|--------------------------------------------------|---|---|----|
|                                            |                                                                                                                                                                                                                | SD                           | D | A | SA | SD                                               | D | A | SA |
| <u>Degree of Seriousness</u>               |                                                                                                                                                                                                                |                              |   |   |    |                                                  |   |   |    |
| 11.                                        | My hyperemesis was a serious condition.<br><i>My doctor believed that my hyperemesis was a serious condition.</i>                                                                                              | 1                            | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| 12.                                        | My own health was in danger from the hyperemesis.<br><i>My doctor believed that my health was in danger from the hyperemesis.</i>                                                                              | 1                            | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| 13.                                        | I could have died from hyperemesis.<br><i>My doctor believed that I could have died from hyperemesis.</i>                                                                                                      | 1                            | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| 14.                                        | My baby's health was in danger because I had hyperemesis.<br><i>My doctor believed that my baby's health was in danger because I had hyperemesis.</i>                                                          | 1                            | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| 15.                                        | My baby could have died because I had hyperemesis.<br><i>My doctor believed that my baby could have died because I had hyperemesis.</i>                                                                        | 1                            | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| 16.                                        | I needed close medical attention for my hyperemesis.<br><i>My doctor believed that I needed close medical attention for my hyperemesis.</i>                                                                    | 1                            | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| <u>Extent of Impact on Patients' Lives</u> |                                                                                                                                                                                                                |                              |   |   |    |                                                  |   |   |    |
| 17.                                        | My hyperemesis interfered with my job. [occupational functioning]<br><i>My doctor believed that my hyperemesis interfered with my job.</i>                                                                     | 1                            | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| 18.                                        | My hyperemesis interfered with my ability to perform my daily activities. [day-to-day functioning]<br><i>My doctor believed that my hyperemesis interfered with my ability to perform my daily activities.</i> | 1                            | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| 19.                                        | I participated in fewer social activities because I had hyperemesis. [social functioning]<br><i>My doctor believed that I participated in fewer social activities because I had hyperemesis.</i>               | 1                            | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
| 20.                                        | Having hyperemesis created a strain on my family relationships. [family functioning]<br><i>My doctor believed that having hyperemesis created a strain on my family relationships.</i>                         | 1                            | 2 | 3 | 4  | 1                                                | 2 | 3 | 4  |
|                                            |                                                                                                                                                                                                                | [* Return to Instruction #2] |   |   |    | [* Proceed to CSQ-8]                             |   |   |    |

### Open Ended Questions

[\*\* Ask open-ended questions after Humanism Scale]

We are almost finished. There are six questions left. In the next set of questions there are no pre-set answer responses (e.g., strongly disagree, agree, etc.). I would like you to answer the question in your own words. Again, your opinion is important. There are no right or wrong answers to any of these questions. Because you will be answering in your own words, I would like to tape record this part of the interview so that I can better remember what you have said. Do you mind if I record these last few questions?

**1. Once you were diagnosed with hyperemesis, was the course of your illness what you expected? (e.g., Did it last as long as you thought it would? Did you expect to be more sick or less sick than you were? etc.)**

prompt: Can you tell me more about that?

**2. What did your doctor say or do that was helpful to you?**

prompt: Can you tell me more about that?

prompt: Can you tell me why that was helpful to you?

**3. What did your doctor say or do that was not helpful to you?**

prompt: Can you tell me more about that?

prompt: Can you tell me why that was not helpful to you?

prompt: What about other doctors or nurses or any other health care professionals-- in the hospital or your doctor's office?

**4. In what ways, if any, did your doctor's bedside manner affect how you felt about yourself?**

(e.g., How she/he interacted with you; How she/he communicated with you; Her/his overall attitude towards you, etc. In other words, how did you feel about yourself after a visit with your doctor? After your doctor left your hospital room or when you left your doctor's office after an appointment, how did you feel?)

prompt: Can you tell me more about that?

**5. What suggestions do you have for doctors who provide care to women with hyperemesis?**

prompt: Can you tell me more about that?

prompt: Why do you think this is important?

**6. Is there anything else that you think is important for me to understand about your experience with hyperemesis?**

### Post-Interview Notes

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## **APPENDIX D**

### **CLIENT SATISFACTION QUESTIONNAIRE**



## CLIENT SATISFACTION QUESTIONNAIRE (CSQ-8)

The next set of questions ask your opinion about the overall medical care you received from your doctor. In responding to these questions I would like you to focus on the following three things:

- 1). Think only about the doctor who took care of you the most during your hyperemesis (again, we are talking about the same doctor that you have been thinking about all along).
- 2). Think only about the care you received for the hyperemesis itself (e.g., do not think about the care you received for your entire pregnancy or for other health problems your doctor has treated you for).
- 3). And, when I talk about the care you received from your doctor, think about both his/her knowledge and technical skills and his/her interpersonal skills (that is, his/her bedside manner).

Is that clear? Would you like me to repeat any of these instructions? Give the answer that best describes your opinion. Sometimes patients are hesitant to say things about their doctors-- either positive or negative. I'd like to remind you that your answers are confidential. And your doctor will not know that you are participating in this study. Again, there are no right or wrong answers. It is your opinion that is important for this study.

### 1. How would you rate the quality of the care you have received from your doctor?

|           |      |      |      |
|-----------|------|------|------|
| 4         | 3    | 2    | 1    |
| Excellent | Good | Fair | Poor |

### 2. Did you get the kind of care from your doctor that you wanted?

|                    |                |                |                 |
|--------------------|----------------|----------------|-----------------|
| 1                  | 2              | 3              | 4               |
| No, definitely not | No, not really | Yes, generally | Yes, definitely |

### 3. To what extent did your doctor meet your needs?

|                                     |                               |                                     |                               |
|-------------------------------------|-------------------------------|-------------------------------------|-------------------------------|
| 4                                   | 3                             | 2                                   | 1                             |
| Almost all of my needs had been met | Most of my needs had been met | Only a few of my needs had been met | None of my needs had been met |

CSQ-8 Continued:

4. If a friend were in need of similar help, would you recommend your doctor to her?

|                    |                      |                 |                 |
|--------------------|----------------------|-----------------|-----------------|
| 1                  | 2                    | 3               | 4               |
| No, definitely not | No, I don't think so | Yes, I think so | Yes, definitely |

5. How satisfied were you with the amount of help you had received from your doctor?

|                    |                                    |                  |                |
|--------------------|------------------------------------|------------------|----------------|
| 1                  | 2                                  | 3                | 4              |
| Quite dissatisfied | Indifferent or mildly dissatisfied | Mostly satisfied | Very satisfied |

6. Did your doctor help you to deal more effectively with your hyperemesis?

|                                 |                    |                                |                                        |
|---------------------------------|--------------------|--------------------------------|----------------------------------------|
| 4                               | 3                  | 2                              | 1                                      |
| Yes, she/he helped a great deal | Yes, she/he helped | No, she/he really did not help | No, she/he seemed to make things worse |

7. In an overall, general sense, how satisfied were you with the care you received from your doctor for hyperemesis?

|                |                  |                                    |                    |
|----------------|------------------|------------------------------------|--------------------|
| 4              | 3                | 2                                  | 1                  |
| Very satisfied | Mostly satisfied | Indifferent or mildly dissatisfied | Quite dissatisfied |

8. If you were to seek medical care again for hyperemesis, would you go back to your doctor?

|                    |                      |                 |                 |
|--------------------|----------------------|-----------------|-----------------|
| 1                  | 2                    | 3               | 4               |
| No, definitely not | No, I don't think so | Yes, I think so | Yes, definitely |

## APPENDIX E

### HUMANISM SCALE

## HUMANISM SCALE

The following questions ask your views on the doctor who took care of you the most during the time you were sick with hyperemesis. Again, this is the same doctor that you have been thinking about for the other questions. People have a wide range of relationships with their doctors. Some people are very happy with their relationship with their doctor, some are not so happy and some have mixed feelings. I'd like to remind you that your answers are completely confidential. Also, there are no right or wrong answers. It is your opinion about your experience that is important in this study.

I will read statements to you and am interested in understanding how strongly you agree or disagree with each statement. After I read each statement, please give the answer that describes how strongly you agree or disagree with the statement. The response choices are the same as they were in earlier questions, except that now a new category is added. Please take a moment to write these categories down on a piece of paper. Strongly Disagree= SD, Disagree= D, Neutral= N (neutral means you don't have an opinion either way), Agree= A, Strongly Agree= SA

|                                                                                               | SD | D | N | A | SA |
|-----------------------------------------------------------------------------------------------|----|---|---|---|----|
| 1. My doctor seemed to take a personal interest in me.                                        | 1  | 2 | 3 | 4 | 5  |
| 2. My doctor asked for my opinion when making decisions about my treatment.                   | 1  | 2 | 3 | 4 | 5  |
| 3. I would bring up personal problems to my doctor.                                           | 1  | 2 | 3 | 4 | 5  |
| 4. My doctor asked about my family.                                                           | 1  | 2 | 3 | 4 | 5  |
| 5. Even when my problem was small, my doctor showed concern for me.                           | 1  | 2 | 3 | 4 | 5  |
| 6. My doctor explained things so I understood.                                                | 1  | 2 | 3 | 4 | 5  |
| 7. I trusted my doctor.                                                                       | 1  | 2 | 3 | 4 | 5  |
| 8. I was treated like a "number" by my doctor.                                                | 5  | 4 | 3 | 2 | 1  |
| 9. I didn't bring up certain things because my doctor would have thought I was stupid.        | 5  | 4 | 3 | 2 | 1  |
| 10. My doctor was concerned when something was bothering me.                                  | 1  | 2 | 3 | 4 | 5  |
| 11. My doctor asked about conditions at work (if you were a homemaker, include this as work). | 1  | 2 | 3 | 4 | 5  |
| 12. My doctor seemed to understand my feelings.                                               | 1  | 2 | 3 | 4 | 5  |
| 13. My doctor usually seemed hurried.                                                         | 5  | 4 | 3 | 2 | 1  |
| 14. I had confidence in my doctor's decisions.                                                | 1  | 2 | 3 | 4 | 5  |
| 15. My doctor was able to "put himself/herself in my shoes."                                  | 1  | 2 | 3 | 4 | 5  |
| 16. Every time I saw my doctor, it seemed that he/she did not remember me.                    | 5  | 4 | 3 | 2 | 1  |
| 17. My doctor cared about me.                                                                 | 1  | 2 | 3 | 4 | 5  |
| 18. My doctor respected my beliefs.                                                           | 1  | 2 | 3 | 4 | 5  |

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**Humanism Scale Cont.**

|                                                                                            | SD | D | N | A | SA |
|--------------------------------------------------------------------------------------------|----|---|---|---|----|
| 19. I would talk to my doctor if something were bothering me.                              | 1  | 2 | 3 | 4 | 5  |
| 20. My doctor took an interest in my home life.                                            | 1  | 2 | 3 | 4 | 5  |
| 21. My doctor was easy to talk to.                                                         | 1  | 2 | 3 | 4 | 5  |
| 22. My doctor was skilled and well-informed about my hyperemesis.                          | 1  | 2 | 3 | 4 | 5  |
| 23. My doctor showed warmth and compassion.                                                | 1  | 2 | 3 | 4 | 5  |
| 24. My doctor seemed to know what I was going through when I told him/her about a problem. | 1  | 2 | 3 | 4 | 5  |

[\*\* Go to Open-Ended Questions]

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