

Patient Experience of Privacy while Participating in Group Healthcare: A Phenomenographic Description

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Boston College

William F. Connell School of Nursing

PATIENT EXPERIENCE OF PRIVACY
WHILE PARTICIPATING IN GROUP HEALTHCARE:
A PHENOMENOGRAPHIC DESCRIPTION

a dissertation

by

LAURIE A. FRIEDMAN

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Patient Experience of Privacy While Participating in Group Healthcare:

A Phenomenographic Description

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ABSTRACT

Purpose: The purpose of this qualitative research was to describe the phenomenon of privacy as experienced and conceptualized by patients who participated in the CenteringPregnancy model of group healthcare.

Background: In healthcare, privacy is an ethical and legal right. Healthcare providers have an obligation to protect patient privacy and confidentiality. Group healthcare is an innovative approach that brings together a group of patients with a team of providers, offering the opportunity for holistic, integrated, and coordinated healthcare. Group healthcare challenges how healthcare providers manage privacy and confidentiality. Knowledge about patients' experiences of privacy during group healthcare such as CenteringPregnancy is fundamental to developing an understanding of the risks and benefits incurred during group healthcare visits. Research focused on uncovering the patient experience of privacy within the context of group healthcare can provide useful direction for improving the patient care experience and health outcomes.

Research Questions: 1) What is the privacy experience of women who participated in CenteringPregnancy? 2) How does the patient experience of privacy in a group healthcare setting differ from the experience of privacy during individual care?

Methods: This qualitative research used phenomenography to examine the experiences of privacy for 15 women who participated in CenteringPregnancy at a large multisite, multispecialty healthcare practice.

Results: Four main concepts related to privacy were identified. *My Privacy: Agency of the Self* emerged as the primary conception of privacy for both group and individual care settings. *My Provider: Protecting My Privacy* focused on the critical role of the group facilitator in protecting confidentiality and establishing group privacy. *The Dynamics of Group Privacy* encompassed the relational processes of trusting, respecting, and sharing. *Benefits of Participating in Group Healthcare* included friendship, comradery, learning, and relief of feelings of isolation, fear, and anxiety.

Conclusions: Women's experiences of privacy within the context of CenteringPregnancy were positive. Findings can guide recruitment efforts and the facilitation and management of the group environment. Healthcare providers can offer a full description of privacy within group healthcare settings as part of recruitment and informed consent and emphasize the shared responsibility for group privacy among all members in the group.

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Table of Contents

Acknowledgements.....	v
List of Tables	xv
Chapter One: Background/Overview of the Study	1
Group Healthcare	3
Other groups addressing health concerns.	5
History of group healthcare.	8
Privacy in Group Healthcare.....	10
Privacy and Patient Experience	11
Statement of the Problem.....	12
Significance of the Problem.....	13
Purpose Statement.....	15
Research Questions	15
Chapter Two: Review of the Literature	16
Privacy in the Setting of Healthcare	16
Codes of ethics for healthcare professionals.....	17
Research About Patient Experience of Privacy	21
Patient experience of privacy in healthcare.	21
Role of privacy within the measurement of patient satisfaction...	25
Four Models of Group Healthcare	27
The Chronic Care Clinic model.	28
The Cooperative Health Care Clinic model.....	33

The CenteringPregnancy model.....	36
The Shared Medical Appointment model.....	42
Group Healthcare Research	45
Randomized clinical trial research: Group healthcare.....	46
Descriptive and qualitative research findings: Group healthcare.....	62
Summary	69
Chapter Three: Method	71
Qualitative Design: Phenomenography	72
Philosophical foundations of Phenomenography.....	73
Rationale for Descriptive Phenomenography	77
The Researcher’s Professional Background	79
Setting	81
Sample.....	83
Inclusion criteria	83
Exclusion criteria	83
Sample size.	85
Participant recruitment.....	86
Protection of Human Subjects and Research Integrity	88
Institutional Review Boards.....	88
Informed consent.	89
Confidentiality and data security.	90
Data Collection	91

Member-checking interviews.....	92
Data Analysis	93
Qualitative Rigor and Validity	95
Chapter Four: Results	99
Demographic Characteristics of the Study Participants.....	101
Organizing Concept 1 – My Privacy: Agency of the Self	105
Privacy is voluntary participation in group healthcare	108
Privacy is choosing what feelings and experiences I keep private	109
Privacy matters less when my pregnancy is healthy.....	112
Privacy is not being seen or heard during the individual check-in and exam	113
Privacy is staying dressed for physical health examinations, just lifting up my shirt.....	114
Privacy is partial behind a curtain or plant divider.	115
Privacy is not being overheard when speaking individually with my provider.....	117
Privacy is white noise or music that masks my conversation with my provider.....	118
Privacy is retaining control of my health information	119
Privacy is taking my own weight and blood pressure.....	121
Privacy is getting bad news about me first.	123

Privacy is communicating using an Electronic Health Record.....	126
Privacy is the availability of individual care and communication outside of the group.	127
Organizing Concept 2 – My Provider: Protecting My Privacy.....	129
Privacy is when my provider protects my personal information	131
Privacy is my provider asking my permission before sharing personal information.	133
Privacy is my provider respecting the privacy of others.....	135
Organizing Concept 3 – The Relational Dynamics of Group Privacy:	
Trusting, Respecting, and Sharing	136
Privacy is trusting that others will keep my personal information confidential	139
Privacy is a mutually reinforcing experience of respecting others and feeling respected.....	141
Privacy is not pushing others to share.....	141
Privacy is giving space to others and not eavesdropping.	144
Privacy is sharing on one’s own terms	147
Privacy is not feeling pushed or feeling pressured to share.	151

Privacy is giving permission for my information to be shared.....	153
Organizing Concept 4 – The Benefits of Participating in Group Healthcare	157
Privacy in the group promotes friendship and a feeling of intimacy	159
Privacy is including intimate partners.....	164
Privacy is excluding men.....	167
Privacy enables comradery in the sharing of the experience of becoming mothers.....	167
Privacy allows sharing that can diminish fear and anxiety.....	171
Privacy supports learning through sharing experiences.....	172
Summary.....	176
Chapter Five: Discussion.....	179
Major Findings.....	179
My Privacy: Agency of The Self.....	180
My Provider: Protecting My Privacy.....	187
Relational Dynamics of Group Privacy: Trusting, Respecting, and Sharing.....	196
Trusting.....	198
Respecting.....	200
Sharing.....	204

The Benefits of Participating in Group Healthcare.....	206
Yalom’s therapeutic factors in group therapy.....	207
Limitations.....	216
Implications for Nursing Practice	218
Implications for Nursing Research and Future Scholarship	220
Implications for Nursing Education.....	222
Implications for Policy.....	226
References.....	231
Appendices.....	258
APPENDIX A – Confidentiality Agreement.....	258
APPENDIX B – Facilitator Email	259
APPENDIX C – Study Fact Sheet.....	261
APPENDIX D – Participant Invitation Letter	263
APPENDIX E – Participant Information Sheet.....	265
APPENDIX F – Permission to Contact Form	269
APPENDIX G– Interview Protocol Guide	270

List of Tables

Table 1. Mazer’s Categories of Meaning and Associated Themes/Aspects	22
Table 2. Mazer’s Hierarchy of Privacy Needs	23
Table 3. The Elements and Goals of the Chronic Care Model (CCM).....	33
Table 4. Demographic Characteristics of Study Participants	102
Table 5. Privacy Statements - My Privacy: Agency of The Self	107
Table 6. Privacy Statements - My Provider: Protecting My Privacy	131
Table 7. Privacy Statements – Relational Dynamics of Group Privacy: Trusting, Respecting, And Sharing	138
Table 8. Privacy Statements - The Benefits of Participating in Group Healthcare	159
Table 9. Privacy Statements - My Privacy: Agency of The Self	181
Table 10. Privacy Statements - My Provider: Protecting My Privacy	188
Table 11. Privacy Statements - Relational Dynamics of Group Privacy: Trusting, Respecting, And Sharing	197
Table 12. Privacy Statements – Sharing	205
Table 13. Privacy Statements – The Benefits of Participating in Group Healthcare	207

Chapter One: Background/Overview of the Study

Privacy is a complex social, legal, and ethical concept addressing the protection of individual and social rights (Westin, 1970). The right to privacy is included under Article 12 of the Universal Declaration of Human Rights: “No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honor and reputation. Everyone has the right to the protection of the law against such interference or attacks” (United Nations, 1948). However, it is only recently that strong protection for the individual privacy rights of all, including women and marginalized groups, has become a reality rather than an ideal (Keizer, 2012; Smith, 1997).

The promise of a healthcare provider to safeguard patient privacy has been traced to the the late 5th Century BCE Greek Hippocratic Oath, which includes the following statement:

Whatever, in the course of my practice, I may see or hear (even when not invited), whatever I may happen to obtain knowledge of, if it be not proper to repeat it, I will keep sacred and secret within my own breast (Copeland, 1825, p. 258).

Broad ethical mandates for healthcare providers to protect patient privacy and confidentiality continue to be prescribed in current professional codes of ethics (American College of Nurse-Midwives [ACNM], 2015; American Medical Association [AMA], 2015; American Nurses Association [ANA], 2015).

Additional guidelines and obligations are detailed in the regulatory mandates of

the Privacy Rule promulgated in 2003 as required by the Health Insurance Portability and Accountability Act of 1996, commonly known as HIPAA (US Department of Health and Human Services Administration [USDHHS], 2003).

Within the context of healthcare, the privacy of the patient is modified by the social power of physicians and other health professionals. Another factor that has an impact on privacy is the health status of the patient (Mazer, 2011). With the advent of electronic medical records, integrated care systems, and the Internet new opportunities to improve care have arisen within the realm of healthcare. Yet these technologies also profoundly have challenged the healthcare system's ability to protect individual privacy, confidentiality, and control over the accuracy and flow of personal health information (Grace, 2014; Peel, 2015). Furthermore, the social understanding of patient privacy has been strongly influenced by the stigma of illness and disease (Frois, 2009). HIV/AIDs offers one example of the complexities that can arise in protecting patient privacy within the context of an infectious disease epidemic with modes of transmission that include sexual activity and illicit drug use (Cline & McKenzie, 2000). Patient concerns about the stigma of a cancer diagnosis that vary by age and culture provide another example (Deshefy-Longhi, Dixon, Olsen and Grey, 2004).

Medicine, midwifery, and nursing historically have been practiced within dyadic provider-patient relationships. Until the rise of the modern hospital, most healthcare occurred in the privacy of the patient's home (Buhler-Wilkerson, 2001). The shift of care into hospitals allowed providers to group patients in one

place and gave the patients access to shared technologies and caregiver skills. However, the move to hospitals also created an environment with significant challenges to patient privacy (Mazer, 2012). Less private care in shared spaces continued into the 20th century for the poor, the institutionalized, and the military, and for public health initiatives like preventive vaccinations for masses of people.

Group Healthcare

Group healthcare brings together a group of patients with a team of providers, offering the opportunity for more holistic, integrated, and coordinated healthcare. Group healthcare is an innovation that was designed to address problems with individual healthcare visits that have been encountered by patients, providers, and healthcare systems (Rising, Kennedy, & Klima, 2004; Scott et al., 2004; Wagner, E. H., Austin, & Von Korff, 1995). These problems include lack of access to healthcare, poor quality, unsatisfactory patient experiences, fragmentation of care and increasing cost (Carlson & Lowe, 2006; Noffsinger, 2009; Novick, 2009; Rising, Kennedy, & Klima, 2004; Weinger, 2003). Group healthcare was developed in the 1990s, amidst policy efforts to improve healthcare in the United States. Improvement efforts focused on healthcare quality, access and cost have been ongoing for at least the past fifty years and continue to the present (Berwick, Noland, & Whittington, 2008; Mason, Leavitt, & Chaffee, 2012).

Four models of group healthcare were initiated in the United States as a solution to some of the identified problems. These models are Chronic Care

Clinics, Cooperative Health Care Clinics, CenteringPregnancy, and Shared Medical Appointments. Two of these models, Chronic Care Clinics (Wagner, E. H., Austin, & Von Korff, 1996) and Cooperative Health Care Clinics (Scott et al., 2004), were developed within managed care systems. They intentionally focused on serving patients with chronic illnesses or problems affecting one's health that require lifestyle modifications. A third model, CenteringPregnancy, was developed to provide prenatal care in a group setting (Centering Healthcare Institute [CHI], 2015b). This model has expanded to include CenteringParenting, which provides care to women and newborns during the first year after birth (Bloomfield & Rising, 2013). Shared Medical Appointments, a fourth model, was built upon earlier models of group healthcare. The Shared Medical Appointments model has been widely adapted for many types of episodic and ongoing health needs of patients in the areas of primary care, specialty care, surgical care, and chronic, disease-specific care (Noffsinger, 2009). Given these models, group healthcare was defined for the purposes of this dissertation as the provision of care to a group of patients who receive the services of one or more healthcare providers at the same time.

Although the use of group healthcare has grown over the past 25 years (Edelman et al., 2012), most healthcare in the United States still occurs in an office setting where individual providers care for patients in small exam rooms or in hospital settings where teams of providers, usually led by physicians, care for individual patients (Buhler-Wilderson, 2001; Bynum, 2008; Rooks, 1997).

According to the latest statistics publicly available on the Center for Disease Control and Prevention website, in 2010 there were 1.2 billion ambulatory care visits (Center for Disease Control and Prevention [CDC], 2011a) and 34.4 million hospital discharges (CDC, 2011b). However, no more recent statistics from the CDC related to these parameters were available for comparison with the 2010 figures.

Other groups addressing health concerns. There are other groups with health promotion goals that do not fit into the definition of group healthcare used in this research study. Examples include group psychotherapy and counseling, patient education and health promotion, and support, self-management, and self-help groups. The differences between group healthcare and these other groups are briefly outlined in the next section.

Group psychotherapy is a common mode of mental health treatment, although it is still less frequently used than individual therapy. There is a rich body of research to support the effectiveness of group psychotherapy in addressing a variety of mental and behavioral health concerns in multiple settings (Yalom, 2005). Like group healthcare, psychotherapy and counseling groups are led or facilitated by mental health professionals. And though they may incorporate some aspects of medication management and laboratory surveillance

into group care, psychotherapy and counseling groups are focused on mental rather than physical healthcare (Conyne, 2010).¹

Patient education and health promotion are often conducted in a group setting in medical offices, hospitals, work places, and community settings (Lowenstein, Foord-May, & Romano, 2009; Minelli & Breckon, 2009; Pender, Murdaugh, & Parsons, 2002). These courses, workshops, or classes can range in size, didactic approach, cost, and effectiveness. Childbirth education classes are a type of patient education that traditionally involve groups of pregnant women and their partners learning about pregnancy, birth, breastfeeding, newborn care, and parenting (Lamaze, 2011; Varney, 2004; Walker & Worrell, 2008). Like group healthcare, these patient education and health promotion groups are usually led by health professionals but are focused on education rather than healthcare. Other models of peer education have been developed by patient advocacy groups, like the Alzheimer's Association and Parents Anonymous (Kurtz, 1997). In the past 20 years, the Internet has greatly expanded access to medical and health information as well as provided the opportunity to use social media as a tool for health promotion, often replacing classroom-based patient education (Balatsoukas, Kennedy, Buchan, & Ainsworth, 2015). For example, childbearing women are turning increasingly to the Internet and text messaging services for

¹ This distinction between mental and physical health is blurring as health science progresses, yet it continues to be perpetuated by cultural beliefs and healthcare finances. Nursing as a discipline has attempted to reunify this division (Willis, Grace, & Roy, 2008).

information about pregnancy, childbirth, breastfeeding, and newborn care (Declercq, Sakala, Corry, Applebaum, & Herrlich, 2013).

In contrast to groups led by professionals, self-help groups have been characterized by peer leadership and sometimes limited professional involvement (Kurtz, 1997). Examples of self-help groups outside of the healthcare system include Alcoholics Anonymous, founded in 1935 to address alcoholism, and Weight Watchers, founded in 1963 to address obesity (Kurtz, 1997). Using a self-help approach, feminist health activists expanded women's "consciousness raising" groups in the 70s and 80s, teaching women about their bodies through self-gynecological examination in a group setting (Federation of Feminist Women's Health Centers, 1981).

The concept of self-management was championed by Kate Lorig (2015) and others caring for people with chronic illnesses to encompass everything a person and their family must do to manage and cope with such illnesses (Grey, Schulman-Green, Knafl, & Reynolds, 2015; Schulman-Green et al., 2012). In this conceptualization, health professionals are essential partners and resources within the healthcare system, but the individual and their family remain at the center of the processes of focusing on illness needs, activating resources, and living with the condition (Grey et al., 2015, p. 165). Self-management and support groups within this framework are most often peer led rather than professionally led.

The feature that distinguishes group healthcare from all of these other groups is the participation of health professionals who provide physical

assessments within the group space. All four models of group healthcare presently utilized in the United States were designed to integrate the provision of focused exams into the teaching, learning, and social support that occurs during the time the groups meet together.

History of group healthcare. The developers of currently used models of group healthcare trace the origins of the idea to early group healthcare experiments. In Leddick's (2010) review of the history of group psychotherapy, the author noted that Dr. Joseph Hersey Pratt (1872 – 1956) was one of the pioneering physicians who worked with groups of patients. According to Leddick, Dr. Pratt wrote of his work with patients with tuberculosis and their treatment that included quarantine for six months in sanatoriums. He designated time efficiency as a benefit afforded by seeing patients in a group and described how the patients in his groups were able to offer one another emotional support (Leddick, 2010, p. 53).

In the discipline of nursing, Feldman (1974) offered one of the earliest published descriptions of contemporary group healthcare. Feldman's focus was on describing "cluster visits" developed by pediatric nurse practitioners for mothers and infants at Kaiser-Permanente Medical Center in San Francisco in the early 1970s. Feldman attributed the idea for her cluster visit approach to a seminal nursing article written by Gozzi, Austin, and Yankauer (1970) in which they referred to a group healthcare approach being used in the practice of a

pediatric nurse practitioner. The nurse practitioner role was a newly developing role within the profession of nursing at that time in the United States.

Models of group healthcare have offered solutions to some of the problems inherent in the individual-visits model of healthcare described earlier. These problems have included a lack of access to healthcare, poor quality, fragmentation of care, rising costs, and unsatisfactory patient experiences (Bartley & Haney, 2010; Jaber, Braksmayer, & Trilling, 2005; Manant & Dodgson, 2011). In particular, the pressure on healthcare providers to accommodate higher numbers of patients has created a lack of time for complete, coordinated care, patient education, and thoughtful discussions that are required for shared medical decision-making such as treatment options and informed consent (Halfon, Stevens, Larson, & Olson, 2011). Primary care providers have found the inclusion of recommended patient education and health promotion increasingly difficult to provide successfully within the 10-15 minutes of time allotted for individual care visits in many settings. Additional problems with individual visits include patient feelings of isolation, unmet needs for social support and relationship, and the medicalization of normal life transitions such as childbirth and menopause (Noffsinger, 2009; Rising, 1998).

By offering an alternative approach to the individual-visit model of healthcare, team coordination may occur before, during, or after group healthcare sessions. As noted in the literature, the group healthcare models can increase patient participation in self-management, improve patient satisfaction,

successfully support changes in health behaviors, and provide more efficient use of the resources within healthcare organizations (Centering Healthcare Institute [CHI], 2011; Noffsinger, 2009). Group healthcare moves patients and providers out of isolated, individual exam rooms into a larger shared space where team healthcare can occur with a group of patients (Noffsinger, 2009). Depending on the model, anywhere from 8 to 20 patients, and sometimes their family or support persons, participate together in a group setting in which providers and patients can listen to and learn from one another.

Researchers interested in the implementation, outcomes, challenges and benefits of group healthcare have examined health and quality of care outcomes, cost, resource utilization, and patient experience. Early reports were mainly descriptive, including data collected as part of program evaluation or quality improvement efforts within healthcare organizations. Several randomized controlled trials comparing group healthcare to usual care have been conducted and published (Coleman, E. A. et al., 2001; Ickovics et al., 2011; Ickovics et al., 2007; Kennedy et al., 2007; Sadur et al., 1999; Scott et al., 2004; Trento et al., 2004; Wagner E. H. et al., 2001; Wagner, E. H., Austin, & Van Korff, 1996). The findings of these studies are described in detail in the subsequent chapter focused on a review of the literature.

Privacy in Group Healthcare

Privacy in the group setting is accounted for in each of the four models of group healthcare. All models include a provision for a group leader to ask group

participants to sign a confidentiality agreement. As implemented in most organizations, participation in group healthcare is voluntary. Even when group healthcare is the dominant model in a given system, a patient usually can choose to obtain care elsewhere. Privacy and confidentiality concerns are issues raised by patients when they consider whether to choose group healthcare and are also expressed as reasons why some patients choose not to participate in group healthcare (Baldwin & Phillips, 2011; Phillippi & Meyers, 2013; Wagner, E. H. et al., 2001; Wong, Lavoie, Browne, MacLeod and Chongo, 2013).

Privacy and Patient Experience

Within the literature on the patient experience of healthcare, the construct of patient satisfaction has been a major emphasis in assessing and evaluating the patient experience (National Committee for Quality Assurance, 2011; Mazer, 2012). Privacy is one of many items measured in commonly used patient satisfaction surveys like Press Ganey and Gallup (Wolf & Palmer, 2015).

Although commonly used measures of patient satisfaction incorporate privacy as an item in the measurement and evaluation of the patient's experience (Heyworth et al., 2014; Nayeri & Aghajani, 2010; Wagner, E. H. et al., 2001), researchers have given very little attention to fully describing and explicating the phenomenon of privacy as experienced and conceptualized by patients participating in group healthcare. An exception is a published study by Wong, Lavoie, Browne, MacLeod and Chongo (2013) that specifically addressed the patient experience of privacy in group healthcare as part of a mixed-methods

research study evaluating the impact of group medical visits on the quality of primary healthcare in northern rural communities in British Columbia.

Statement of the Problem

Group models of healthcare were developed in response to problems with the individual delivery of medical care. Despite the benefits that have been evidenced with various models of group healthcare, the potential to violate patient privacy and confidentiality is a significant issue raised in the recent literature (Novick et al., 2011; Wong et al., 2013). Privacy, and its affects on the patient experience, has emerged as a concern of both patients and providers (Phillippi & Myers, 2013; Novick et al., 2011; Wong et al., 2013).

Research questions related to the experience of privacy within the context of group healthcare are largely unanswered. Although research questions about how group healthcare affects patient outcomes has been partially addressed in the literature described earlier, privacy as a patient experience within the context of group healthcare and its influences on health have not been systematically studied. Despite the challenges related to privacy inherent in group healthcare such as the reluctance of patients to participate in a group due to fears about disclosure (Phillippi & Meyers, 2013; Novick et al., 2011; Wong et al., 2013), the research literature on group healthcare and patient experience has focused almost exclusively on clinical and system of care outcomes (Edelman et al., 2012).

Significance of the Problem

Group healthcare is a change in the way ambulatory healthcare is offered to patients with a variety of health concerns and illnesses. Research on group healthcare and patient outcomes has begun to suggest that group healthcare may offer ways to improve health outcomes, increase patient satisfaction, and create cost savings through more efficient use of healthcare resources. What remains unexplored is how patients and providers experience healthcare in groups, including the experience and conceptualization of privacy within the context of group healthcare from the patient's perspective. How group healthcare influences the relationship between the patient and provider has yet to be known and described completely.

Given the important ethical and legal concerns about privacy in the provision of good patient care and the state of the science on the patient experience of privacy within the context of group healthcare, further descriptive research was needed to identify the patient experience of privacy within this context. Descriptive research was also needed to better understand how the experience of privacy differs from that experienced in an individual care visit with a healthcare provider. Privacy as experienced and conceptualized by patients participating in group healthcare may reveal various ways that privacy is a concern for patients as well as privacy-related risks and benefits that heretofore have not been described in depth.

With the under-developed state of science related to the phenomenon of privacy within the context of group healthcare, providers are at risk for being unfamiliar with the experiences and conceptions of privacy as understood by patients participating in group healthcare (Wong et al., 2013). Thus, it has become critically important for nursing and other healthcare scholars to add to the knowledge base of nursing and other health sciences about the phenomenon of privacy within the context of group healthcare. Healthcare providers need to know how privacy is experienced and conceptualized by patients within group healthcare and how group healthcare affects the patient experience. This type of knowledge can assist healthcare providers to minimize risks/harm, increase patient satisfaction with the group healthcare experience, and expand access to the benefits of group healthcare. Ultimately healthcare providers are responsible to facilitate group healthcare in a manner that safeguards the patient's privacy and confidentiality (codes of ethics).

The phenomenon of privacy as experienced and conceptualized by patients participating in group healthcare needed to be described in depth. Thus, qualitative research to uncover first-person reflections and remembrances of the experience of privacy by patients participating in group healthcare was pre-requisite to advancing knowledge in this substantive area of inquiry. Knowledge about the patient experience of privacy within the context of group healthcare, such as CenteringPregnancy, can be useful for clinical practice. With important ethical and legal concerns about privacy in the provision of good patient care, a

qualitative, descriptive phenomenographic research study was conducted to explore privacy as an important and integral component of the overall patient experience of group healthcare.

Purpose Statement

The purpose of this research was to describe the phenomenon of privacy as experienced and conceptualized by patients who participated in the CenteringPregnancy model of group healthcare. This research provided a foundation for developing knowledge about privacy experiences within the context of group healthcare and clarified how group healthcare affected the patient care experience.

Research Questions

This study addressed the following research questions:

1. What is the privacy experience of women who participated in the CenteringPregnancy model of group healthcare?
2. How does the patient experience of privacy in a group healthcare setting differ from the patient experience of privacy during individual care?

Chapter Two: Review of the Literature

Chapter two is formed in five sections. The first section provides a review of selected literature pertinent to the description of the concept of “privacy” as it relates to healthcare. In the second section, research about the patient experience of privacy and its relation to patient satisfaction is reviewed. The third section offers a description from the literature of the four models of group healthcare presently used in the United States (Chronic Care Clinics, Cooperative Health Care Clinics, CenteringPregnancy, and Shared Medical Appointments). In the fourth section, both quantitative and qualitative research about group healthcare is reviewed. Finally, knowledge gaps related to privacy as experienced by patients in group healthcare are summarized. These knowledge gaps are then linked to the research questions.

Privacy in the Setting of Healthcare

Privacy is a concept with multiple definitions and complex meanings that is threaded throughout our intimate relationships and interactions with our largest social institutions (Smith, 1997). In her work on the hospitalized patient experience of privacy, Mazer (2011) traced the roots of Western ideas about privacy back to the Biblical story of the Garden of Eden. She noted that it is only after eating of the fruit of knowledge that Adam and Eve recognized their nakedness and covered their private body parts as they were banished from Paradise by God for disobedience (p. 34).

Our contemporary understanding of the concept of privacy and the experience of privacy have been profoundly changed and challenged by technology (Keizer, 2012). Rarely a day goes by without news reports of the occurrence of data security breaches of personal identifying information, surveillance efforts by known and unknown entities that impinge on privacy, and the potential or actual harm created by the gathering of personal information for security and commercial purposes (Jarvis, 2011). Additionally, privacy has particular meanings and importance in the setting of healthcare. One indication of the importance of privacy within the context of healthcare is the inclusion in the codes of ethics for physicians, midwives, nurses and other healthcare providers of a professional obligation to protect patient privacy. A brief summary of how these codes of ethics address the meaning and significance of privacy within the context of healthcare is provided below.

Codes of ethics for healthcare professionals. Included within the *Code of Medical Ethics* of the American Medical Association (AMA, 2015) is a provision for the patient's right to privacy as highlighted within the Fourth Principles of Medical Ethics (IV).

A physician shall respect the rights of patients, colleagues, and other health professionals, and shall safeguard patient confidences and privacy within the constraints of the law (p. 58).

This principle, as well as eight principles in the *Code of Medical Ethics*, is supported by opinions authored by the AMA Council on Ethical and Judicial

Affairs. These are updated every two years to include extensive case law and other references upon which the opinions are based.

Privacy is a patient right referred to in many of the opinions on social policy issues such as abortion and genetic testing, confidentiality, and the physician-patient relationship. The opinion of the AMA Council on Ethical and Judicial Affairs about *Privacy in the Context of Health Care* defines four major forms of patient privacy.

Physicians must seek to protect patient privacy in all of its forms, including (1) physical, which focuses on individuals and their personal spaces, (2) informational, which involves specific personal data, (3) decisional, which focuses on personal choices, and (4) associational, which refers to family or other intimate relations. Such respect for patient privacy is a fundamental expression of patient autonomy and is a prerequisite to building the trust that is at the core of the patient-physician relationship (AMA, 2015, p. 385).

Similarly, the statements included in the American College of Nurse-Midwives (2015) *Code of Ethics* that address privacy and confidentiality mandate that midwives in all aspects of their professional practice will provide an environment to protect privacy and maintain confidentiality except in rare cases. The following quotes from the *Code of Ethics* of the American College of Nurse-Midwives (2015) emphasized this mandate:

Provide an environment where privacy is protected and in which all pertinent information is shared without bias, coercion, or deception (p. 7).
Maintain confidentiality except where disclosure is mandated by law (p. 8).

The explanatory statement for the protection of privacy included a reference to HIPAA protections for medical records. Also included is the recognition that protecting personal privacy can be challenging for the healthcare provider (midwife) and that “the midwife should respect the woman’s choice of people who may invade that privacy, including hospital personnel, and her choice of location for disclosing sensitive information (ACNM, 2015, p. 7).

Privacy is defined by the American Nurses Association (2015) Interpretive Statements for the *Code of Ethics for Nurses* as “the right to control access to, and disclosure or nondisclosure of, information pertaining to oneself and to control the circumstances, timing and extent to which information may be disclosed (p. 9). The following statement extracted from the *Code of Ethics for Nurses* highlighted the issue of confidentiality:

Confidentiality pertains to the nondisclosure of personal information that has been communicated within the nurse-patient relationship...The nurse has a duty to maintain confidentiality of all patient information, both personal and clinical in the work setting and off duty in all venues, including social media or any other means of communication...The duty to maintain confidentiality is not absolute and may be limited, as

necessary to protect the patient or other parties, or by law or regulation such as mandated reporting for safety or public health reasons (pp. 9-10).

The definitions and meanings of privacy described in these professional codes of ethics are founded in ideal moral principles and legal ideas about rights of persons. The ethical codes of various healthcare professional groups have been constructed in an attempt to clarify standards for professional practice. However, the ethical codes cannot provide solutions to conflicts of principles that occur in actual clinical practice (Grace, 2014; Moskop, Marco, Larkin, Geiderman, & Derse, 2005).

Healthcare providers and healthcare organizations are bound by the Privacy Rule promulgated in 2003 as part of the Health Insurance Portability and Accountability Act – HIPAA (USDHHS, 2003). Healthcare providers and patients range in their understanding of what these HIPAA regulations and other regulations and laws regarding privacy and healthcare actually protect and require (Anderson, 2007; Olsen, Dixon, Gray, Deshefy-Longhi, & Demarest, 2005).

Grace (2005) advised healthcare professionals “to disclose only as much information as is necessary to permit optimal care and only information that is pertinent to the situation” (p. 115). The complexity of professional teamwork; electronic and paper documentation of healthcare; financing and payment of healthcare; face-to-face, email, phone and video communication between providers and patients are other factors that create countless opportunities for privacy to be violated and private information to leak out beyond the “ideal” wall

of securely protected patient privacy (Chadwick, 2012; Moskop et al., 2005; Rotenberg, Scott, & Horwitz, 2015).

Research About Patient Experience of Privacy

Patient experience of privacy in healthcare. In a phenomenographic description of the patient experience of privacy in healthcare, Mazer (2011, 2012) conducted in-depth qualitative research interviews with 14 patients age 63 and older about their experiences of hospitalization and their perceptions about the subjective meaning and value of privacy. Mazer's phenomenographic analysis of the interviews revealed a complex set of ways in which patients described their experience of privacy in healthcare. She developed a typology of how the patient experience of privacy changed in relationship to the functional status of the patient during the trajectory/course of the hospitalization and illness experience.

Based on her analysis of the interview data, Mazer grouped patients' experiences into conceptions of privacy captured in 14 different themes. She identified two primary aspects that she used to characterize the themes. First, Mazer identified *what* patients defined privacy to be as central to the themes; secondly, she identified what patients valued about *how* privacy was provided by healthcare providers. Mazer described six categories of meaning to capture the 14 themes and arranged the meanings and associated themes into a hierarchy (Mazer, 2012, p. 6) as depicted in Table 1.

Table 1.

Mazer's Categories of Meaning and Associated Themes/Aspects

Categories of Meaning	Associated Themes/Aspects
Self-interest: core of an individual	Privacy is autonomy, ownership Privacy is one's business (my business is my business)
Protection of Self from being subjected to others	Privacy is not having to tell anyone anything, not having to respond to anyone Privacy is not being subjected to anyone else's sounds/words/discussions
Defense of Self in relationship to the other	Privacy is being in control of one's life Privacy is control over my own body
Safe-guarding of Self from invasion by the other	Privacy is a physical place and space Privacy is being alone
Self in relationship to perception of others' judgment	Privacy is hiding secrets, being ashamed of something
Self about Self-perception of circumstances	Privacy is dangerous Privacy is personal Privacy is not always important Privacy is being left alone Privacy is lonely

(Mazer, 2011, p. 132)

Mazer further placed the constructed hierarchy of patient privacy meanings in relationship to Maslow's Hierarchy of Needs in order to offer clarity of their interpretation and support care providers in their ability to assess and interpret the privacy experiences and privacy needs of patients.

Table 2.

Mazer's Hierarchy of Privacy Needs

Wholeness: Has control over own life and boundaries; Privacy needs are dormant unless violated	Privacy/Openness Balance
Well enough to want autonomy and self-reliance	Privacy is very important
Interdependence with family and friends	Privacy begins to matter
Hospital providers meet expectations for care	Privacy has little importance
Physical discomfort and instability	Privacy is irrelevant

(Mazer, 2011, p. 169)

Mazer's research focused on the complexity of patients' experiences and understanding of privacy. It illuminated the contextual nature of the varied meanings of privacy. She found that patients described their experience of letting go of concerns for privacy during health emergencies and in vulnerable care situations. However, she also found that patient's understanding of privacy remained interwoven with their sense of self despite situations where their desire for privacy was put aside. What this meant for the patients in Mazer's study was that moments where they experienced violations of privacy were later placed into context.

An aspect of privacy emphasized by her alignment of patient experiences with Maslow's hierarchy of needs is the contextual change in the value of privacy within the patient experience. Patients realized they were relinquishing privacy in order to receive care in emergency situations and expressed an understanding that relinquishing privacy was necessary under the circumstances. As patients increased in function and wellness, privacy became more explicitly valued. However, Mazer concluded that this process was individualized to the unique patient's self. This finding led her to emphasize the importance of individualized assessment regarding patient desires and concerns regarding privacy at each stage of their hospitalization (Mazer, 2012).

Olsen, Dixon, Grey, Deshefy-Longhi, and Demarest (2005) researched privacy concerns of primary care patients ($n=185$) and nurse practitioners ($n=27$) using a quantitative survey based upon results from a preliminary focus group study (Deshefy-Longhi, Dixon, Olsen, & Grey, 2004). They conducted a factor analysis of survey responses and labeled the four factors that emerged: external threats to privacy, degree of importance of privacy, integrity of information management, and trust (p. 532). In comparing patient responses to the responses of nurse practitioners, Olsen et al. (2005) found that both groups expressed a high level of concern about privacy. Important discrepancies between patient and provider responses included a higher ranking of concern about privacy by patients in relation to cancer in contrast to the level of concern expressed by nurse practitioners. The authors attributed the difference between the two groups to

perceptions of stigma associated with the diagnosis of cancer for patients but not for providers (p. 533). They suggested that healthcare providers make individualized assessments about patient privacy concerns in all healthcare encounters and recommended further research into the different perspectives of patients and providers regarding concerns and understanding of privacy in the context of healthcare.

Role of privacy within the measurement of patient satisfaction.

Patient satisfaction is a concept that takes into consideration the patient's perspective and has evolved within the broader areas of patient-centered care, and represents the patient care experience within quality-of-care evaluations (Silvera & Wolf, 2015). Patient satisfaction has yet to be defined clearly for all healthcare settings and types of encounters and has been measured in a variety of ways with varied success. The measurement and evaluation of patient satisfaction with the hospital experience has received more focus than that of patient satisfaction with outpatient experience (Sizmer & Redding, 2010; Mazer, 2012).

As a concept, patient satisfaction involves significant measurement limitations and complexities (Lees, 2011; Entwistle, Firnigl, Ryan, Francis, & Kinghorn, 2012). The most frequently used assessment tools have been criticized for disregarding the confounding factors of time (scores change significantly depending on how long after the episode of care patient satisfaction is measured) and patient expectations (an even more complicated area to assess).

However, these measurement concerns have not prevented the inclusion of patient satisfaction into the quality of care measures mandated by the Affordable Care Act of 2010. Privacy has emerged as an important component of patient satisfaction in both survey research and in-depth qualitative investigations of patient experience (Dodge et al., 2012; Chadwick, 2012; Hargreaves, Sizmur, & Viner, 2012; Mazer, 2012). As a rule, patients who feel that their privacy has been violated or disrespected are not satisfied with their care.

Despite controversies about best practices for measuring patients' perspective on care, government payment to hospitals are now linked to performance on a common instrument, the HCAHPS² survey. The 21 items are designed to assess “how often” patients experienced a critical aspect of hospital care. Privacy is not addressed directly but is captured within the items that asked “During this hospital stay how often did the nurses/physician treat you with courtesy and respect?” (Center for Medicare and Medicaid Services [CMS], 2015a). Katie Owens, a healthcare consultant, emphasized the importance of highlighting the patient experience.

One of the consequences of HCAHPS & CAHPS surveys is that they have placed a spotlight on some areas in healthcare that have sometimes been overlooked in interactions with patients. For example, the interpersonal habits of consistently showing courtesy and respect are clearly important.

² HCAHPS – Hospital Consumer Assessment of Healthcare Providers and Systems.

I do not know a single healthcare employee that starts their day thinking, ‘today I will try my best to be discourteous and disrespectful’. However, as they run busy throughout the day, they may forget to take the time to greet a patient and family in a warm, welcoming manner, ask if he/she would like the door closed for their privacy, or even sit at eye level as they speak to convey respect and show courtesy (Wolf & Palmer, 2013).

Clearly, poor ratings on courtesy and respect require additional drilling down to understand the cause and remedies for improving a poor patient experience. Increasing our understanding of the patient experience of privacy can assist in evaluating and improving how we protect patient privacy and confidentiality in all healthcare settings.

Four Models of Group Healthcare

There are four principal models of group healthcare that have developed within the US over the past 20 years: Chronic Care Clinics, Cooperative Health Care Clinics, CenteringPregnancy and Shared Medical Appointments (Murray & Keverson, 2005). Critical to the development of each of these models of group healthcare was a founder who initially championed their model. Based on the original ideas and experiences of the founders, each model has been developed by multidisciplinary teams of providers in a variety of healthcare settings. The models have addressed problems and deficiencies in the way healthcare has been provided to particular groups of patients as the following review highlights.

A physician, Edward Wagner (1996) developed the Chronic Care Clinic model. Initially Wagner designed groups for frail elderly patients who were frequent users of healthcare services within the Group Health Cooperative of Puget Sound in Seattle, WA (Wagner, E. H. et al., 1995). Wagner and his research team then designed and researched a Chronic Care Clinic targeting diabetic patients (Wagner, E. H. et al., 2001). The Cooperative Health Care Clinic model was developed by physician John Scott along with his colleagues at Kaiser Health in Colorado (Scott et al., 2004) CenteringPregnancy® was designed during the 1990s by Sharon Schindler Rising, a certified nurse-midwife in New Haven, CT, to provide prenatal care to groups of pregnant women and their families (Rising et al., 2004). Lastly, Edward Noffsinger (2009) in California spearheaded the Drop-In Group Medical Appointment (DIGMA) model of group healthcare. Noffsinger, a health psychologist, based the DIGMA model upon his own experiences as a patient having problems accessing healthcare during a personal health crisis. His model is now described as the Shared Medical Appointment (SMA).

The development of each model is described in greater detail in the following section. Then a summary of published research for each of these models of group healthcare is provided.

The Chronic Care Clinic model. Edward Wagner, MD, in association with Eric Coleman, Katie Coleman and others, adapted the Chronic Care Clinic from work started in the United Kingdom in the early 1990s (Wagner, E. H. et al.,

1995). Research comparing outcomes of diabetes care provided by a hospital specialty clinic to care provided by general practitioners in community practices furnished an impetus for the development of this model of group healthcare. One concern among providers and health organizations was whether improvements in care for patients with chronic illness demonstrated in a randomized clinical trial setting could be successfully translated to real-world healthcare settings (Wagner, E. H. et al., 1996). Access to care was found to be a particular problem with centralized, specialty clinic care. Both barriers of transportation and limited time availability for scheduling resulted in a significant limitation to the spread of this type of healthcare to populations that would potentially benefit. Smaller primary care groups in the community were experimenting with group healthcare as a way to provide the comprehensive team care that was available in a specialty clinic.

Adapting the clinical practices and research conducted in the UK that addressed the organization of care for patients with chronic illness to a health maintenance organization setting in the US, E. Wagner and E. Coleman conducted clinical trials of monthly group visits for frail elderly patients who were disproportionately scheduled for ambulatory care visits (Wagner, E. H. et al., 1996; Coleman, E. A. et al., 1999). Wagner and his associates at Group Health in Seattle, WA next formed groups of newly diagnosed diabetic patients who met with a team that included a physician, nurse, nutritionist, and health educator in a monthly series of six sessions designed to address all the patients' medical, educational and social care needs in a two-hour session. This Chronic

Care Clinic model has been applied to other *lifestyle diseases* including obesity, hypertension, hypercholesterolemia and heart disease, as well as other chronic diseases such as arthritis and asthma (Wagner, E. H. et al., 1996).

The original Chronic Care Clinic groups described in the literature were designed with a time-limited education component or episode of healthcare with the goal of supporting newly-diagnosed patients in obtaining the necessary skills for successful self-management of their chronic diseases (Coleman, E. A. et al., 1999). Chronic Care Clinic groups for the frail elderly with multiple diagnoses often had the disadvantages of significant attrition due to dementia, disability and death. Even so, this model continued to provide benefits for patients, providers, and healthcare organizations in some settings (Coleman, E. A. et al., 2001).

Group healthcare was one innovation of several approaches developed to improve care for people with chronic illness. The overarching approach has become known in healthcare policy reform as the *Chronic Care Model* (Coleman, K. et al., 2009a, Coleman, K. et al., 2009b). The clinicians and researchers developing this broader model worked within a capitated health maintenance organization system of organizing, paying for, and delivering healthcare. These organizations had access to population-based information tools. These tools assisted the managed-care organizations in managing information about large numbers of patients available from their electronic medical records, supported the targeted creation of groups, and investigated clinical and cost outcomes. In the financial context of a large, integrated Health Maintenance Organization (HMO),

the promise of improved clinical outcomes could provide short- and long-term cost benefits to the organization, offsetting the added expenses of the resources required to provide group healthcare. However, the setting of fee-for-service healthcare that remains prevalent in the United States has limited the expansion of these models because it limits reimbursement for prevention and longer term improvements in health that provide cost savings. The move to Accountable Care Organizations (ACO) under the Affordable Care Act of 2010 has renewed interest in these models of group healthcare (Edelman et al., 2012).

Two features differentiated the Chronic Care Clinic model from the other three models of group healthcare. First, the focus on a chronic disease diagnosis resulted in fairly homogeneous groups of patients with similar needs for ongoing medical care helping to differentiate it from the other three models. Groups targeted for patients living with a particular disease provided the opportunity to integrate education about self-management and harness the benefits of social support. The patients served by a given Chronic Care Clinic group could all benefit from similar changes in their health behaviors.

As initially developed, the Chronic Care Clinic model involved a time-limited set of sessions, with the idea that newly-diagnosed patients required the most education and support. However, as recommendations for evidenced-based diabetic care have evolved to include ongoing screening and care every three months, group healthcare for patients with diabetes has also evolved through the incorporation of aspects of other group healthcare models. These include drop-in

availability to increase access from the Shared Medical Appointment model and more emphasis on a facilitative process of education and support from the Centering model (Crawford, 2015; Guthrie & Bogue, 2015; Watts et al., 2015).

The second feature that helped to differentiate the Chronic Care Clinic model from the other three models is the orienting framework of the Chronic Care Model as developed by E. H. Wagner, K. Coleman, Lorig and others. This positioned the Chronic Care Clinic model of group healthcare as one approach among many approaches in the larger Chronic Care Model framework used to achieve organizational changes oriented to improve chronic disease care. Included in the following table (Table 3) is a synoptic view of the elements and goals of the Chronic Care Model along with examples of recommended changes to the healthcare system.

Table 3.

The Elements and Goals of the Chronic Care Model (CCM)

CCM Element	Goal	Examples of Changes
Self Management Support	Empower and prepare patients to manage their health and healthcare.	Counseling around self-management becomes a routine part of encounters. Practice is able to refer patients to effective self-management programs within or outside the system.
Decision Support	Promote clinical care that is consistent with scientific evidence and patient preferences.	Guidelines are embedded into daily practice through alerts, flow sheets, etc. Proven provider education modalities such as academic detailing are utilized.
Delivery System Design	Assure the delivery of effective, efficient clinical care and self-management support.	Visits are planned to meet patient needs, and regular follow-up assured. Non-clinician staff is utilized fully. High risk patients are supported via care management programs.
Clinical information systems	Organize patient and population data to facilitate efficient and effective care.	Proactive care planning identifies patients for outreach. Clinical team uses registry information to plan each visit. Practice regularly receives data on its performance.
Healthcare organization	Create a culture, organization and mechanisms that promote safe, high quality care.	Organization leaders visibly support continuous improvement. Incentives encourage quality improvement.
Community Resources	Help patients access needed services in the community.	Patients are regularly referred to useful community resources and encouraged to participate. Medical and community organizations establish partnerships to develop and support needed services.

(Coleman, K. et al., 2009 [Supplemental Appendix 1])

The Cooperative Health Care Clinic model. Perhaps as proof that “great minds think alike”, Dr. John Scott was inspired to create the Cooperative Health Care Clinic Model in 1991 while rushing from room to room at Kaiser

Permanente in Wheat Ridge, CO (Fox, 1996). Similar to the group healthcare of E. H. Wagner and K. Coleman in Seattle (Chronic Care Clinic model), the Cooperative Health Care Clinic model was initially targeted to meet the needs of elderly patients who were frequent users of ambulatory visits, often with multiple disease diagnoses, and with a high potential for hospitalizations. Scott's early research demonstrated effectiveness and cost savings for this model of group healthcare. Patients participating in the Cooperative Care Clinics benefited from improved clinical outcomes, fewer hospitalizations, and fewer medication errors (Scott et al., 2004; Beck et al., 1997).

The Cooperative Health Care Clinic model is portrayed in the literature as including a multi-diagnosis or heterogeneous group of 15-20 elderly patients who attend a group meeting on a monthly basis (Gade, McKenzie, Scott & Venohr, 1998; Houck, Kilo, & Scott, 2003). In descriptions of this model, patients are encouraged, but not required, to attend every group session. Groups are described as being conducted around a large table, with a nurse assessing blood pressures, obtaining blood sugar values, and performing other functions as indicated, while the physician collects focused histories and performs diabetic foot exams or other physical exams as needed and appropriate. The team of providers then offer complete care with referrals, prescriptions, and other care-coordination activities such as laboratory testing accomplished during the session. The care provided by team members is documented in the medical record during or after the session.

Individualized summaries of the visit, plan of care, medications and follow-up recommendations are distributed to each patient.

In this type of group healthcare, educational and social interactions among patients and providers are described as being relaxed and informal (Fox, 1996). Depending on a specific provider's panel of patients, Cooperative Health Care Clinic groups might be scheduled weekly or bimonthly. As with the Chronic Care Clinics, the formation of these groups is described as being dependent on access to information systems that can generate panels of patients who are then deemed appropriate by the healthcare provider to invite to participate in group healthcare.

Both the Chronic Care Clinic and Cooperative Health Care Clinic models have become less distinct from one another as they have developed and been adapted over time. They have been promoted as a group healthcare visit model for many types of patients and within a variety of healthcare settings. A handbook for implementing group healthcare visits was published by the Group Health Cooperative in 2001, in collaboration with Kate Lorig of the Stanford Patient Education Research Center, Dr. John Scott of Kaiser-Colorado, and Colleen Hawes from Group Health in the Olympia district of the state of Washington where Edward Wagner originated his first Chronic Care Clinics (Group Health Cooperative, 2001). The foundations associated with Group Health in Seattle and Kaiser have supported research and dissemination of the Group Health concept as one of several healthcare innovations promoted for improving care. The educational materials, staff training and support of both the

Chronic Care Clinic and Cooperative Health Care Clinic have been more organizationally based and less robustly disseminated than the CenteringPregnancy Model as promoted through the Centering Healthcare Institute (Group Health Cooperative, 2001).

The CenteringPregnancy model. CenteringPregnancy (Rising, 1998) is a model of group healthcare for pregnant women that combines health assessment, social support, and education to provide prenatal care for women and their families. Its basic form has developed into a series of eight to ten group sessions attended by eight to 12 pregnant women with their support persons. Group prenatal visits begin after an initial intake visit that includes a complete history, physical, and lab screenings. Then, women gather for their next monthly visit with eight to twelve pregnant women with similar due dates for a two-hour session facilitated by two healthcare providers. The first six sessions are monthly, then groups meet every two weeks, with a final “reunion” group session after all the women have delivered. This schedule is patterned after usual prenatal care and provides the opportunity for individual care visits between group sessions if necessary to address any complications or patient concerns (DeFrancesco & Rising, 2010; Reid, 2007; Rising, 2005).

At the beginning of each group session, women are encouraged to do as much of the physical assessment as possible - taking their own blood pressure, recording their weight, and calculating gestational age - with assistance as needed. Brief individual exams including fetal heart tones and fetal growth are also

conducted in the group space in a semi-private area at the beginning of the session. The remaining time is spent in active learning and socializing based on a curriculum modified by the interests and learning needs of the group members. Individual visits can be arranged before or after the group, or between sessions, to address problems requiring private exams, complications of pregnancy, or individual counseling (Rising et al., 2004).

In developing the model, Sharon Schindler Rising built on her experience of providing care at the Childbearing Childrearing Center in Minnesota (Rising et al., 2004). This center was a site for low-risk women and their partners to obtain prenatal care from midwives, join support groups with couples of similar gestation, and to continue well-child care. It was founded on the philosophical belief that “a dynamic union of healthcare provider and consumer holds the greatest potential for the personal growth of both. The consumer is viewed as an equal partner in care and works actively with the care provider to develop goals and appropriate means to reach those goals (Rising & Lindell, 1982).

In 1989, the U.S. Public Health Service Expert Panel on Prenatal Care published a landmark document entitled *Caring for Our Future: The Content of Prenatal Care* (US Public Health Service [USPHS], 1989). This multidisciplinary panel determined that many of the components of prenatal care in the US at that time were not supported by evidence of effectiveness. Furthermore, they highlighted that despite evidence to support an empirical association of these components with improved patient outcomes, education and

support to address the emotional and social needs of women and new families was not being included in usual prenatal care. The panel called for the discontinuation of unproven or harmful components of care such as routine urine dipstick testing for glucose and protein at each prenatal visit. Also, the panel called for ongoing research to validate and confirm the effectiveness of possibly effective components of prenatal care. In addition, they called for redesign of healthcare to focus resources on those women and families who would most benefit or were at higher risk for poor outcomes. The findings in this report supported the parallel development of the CenteringPregnancy model that was piloted by Rising during 1993–1994 with 13 prenatal groups in a hospital clinic in New Haven, CT (Novick, 2004).

In order to describe the CenteringPregnancy model more specifically for the purposes of implementation, research, and evaluation, Rising and her colleagues identified what they called the *Essential Elements of CenteringPregnancy* (Tilden, Hersh, Emeis, Weinstein & Caughey, 2014). These elements were based upon their experience and early evaluations of the process and outcomes of group prenatal care. These elements were identified as:

1. Health assessment occurs within the group space.
2. Participants are involved in self-care activities.
3. A facilitative leadership style is used.
4. The group is conducted in a circle.
5. Each session has an overall plan.

6. Attention is given to the core content, although emphasis may vary.
7. There is stability of group leadership.
8. Group conduct honors the contribution of each member.
9. The composition of the group is stable, not rigid.
10. Group size is optimal to promote the process.
11. Involvement of support people is optional.
12. Opportunity for socializing with the group is provided.
13. There is ongoing evaluation of outcomes (Rising et al., 2004, p. 399).

The Essential Elements of CenteringPregnancy do not explicitly mention privacy. This lack of an explicit reference to privacy concerns may be due to an assumed continuation of the protection of privacy within the individual-visit model of the patient-provider relationship. In CenteringPregnancy, training materials and workshops were developed to assist healthcare providers in the implementation of this model of group healthcare-within these materials the issues of privacy and confidentiality are nested within the component of *group conduct*. Group conduct is predicated on honoring the contribution of each member by agreeing to keep group information confidential (Rising, 2005).

The group configuration for CenteringPregnancy is characterized as stable (Rising et al., 2004; Rotundo, 2011). Stable group membership connotes that the members of the group are the pregnant women enrolled in CenteringPregnancy and the healthcare providers who attend all the sessions. Some flexibility in the group configuration and membership can involve the incorporation of new

members in the second or third session, partners attending only some sessions rather than all, or guest speakers who contribute knowledge other than the expertise provided by the group facilitators (Carson & Lowe; 2006). For example, a nutritionist or lactation consultant might join the group for one session. This general consistency of membership is intended to support the growth of trust among group members. A confidentiality agreement is recommended for all pregnant women and support persons participating in the group. A sample confidentiality agreement currently recommended by the Centering Healthcare Institute can be found in Appendix A.

The thirteen elements delineated above have been used to shape the development of CenteringPregnancy. Research about CenteringPregnancy has been widely disseminated in the US and abroad. The CenteringPregnancy model has been adapted to meet the needs of specific healthcare settings and populations including military personnel and families (Foster et al., 2012; Kennedy et al., 2009; Kennedy et al., 2011; Nielsen et al., 2012), adolescents (Grady & Bloom, 2004; Moeller, Vezeau, & Carr, 2007), Spanish-speaking women (Law & Kennedy, 2007; Robertson, Aycock, & Darnell, 2009); Iranian women (Jafari, Eftekhari, Mohammad, & Fotouhi, 2010); and Australian women (Teate, Leap, Rising, & Homer, 2009). The educational component has been enhanced to include specific foci on improving health behaviors that are known to have significant influences on maternal child health, including appropriate pregnancy weight gain (Brumley & Jevitt, 2012), safer sexual practices and HIV prevention

(Ickovics et al., 2011; Ickovics et al., 2007; Kershaw, Magriples, Westdahl, Rising, & Ickovics, 2009), dental health (Skelton et al., 2009); and mindfulness practices (Duncan & Bardacke, 2011).

Within the US during the second decade of the 21st Century, the predominant model for reimbursement of prenatal care continues to be a global provider fee that includes basic prenatal, delivery, and postpartum care (Moos, 2006). This has enabled group prenatal care to be considered cost neutral as long as the efficiencies of group care are balanced with the use of resources. Mooney, Russell, Prairie, Savage and Weeks (2008) reported an analysis of the cost of group healthcare in a small, rural hospital. They noted that the details of the costs of the Centering model have not been reported extensively in the literature. They determined that cost savings began to accrue in their agency when 218-305 women a year participated group healthcare. Their analysis did not include an economic estimate of long-term benefits, like savings from lower rates of premature birth or increase in duration of breastfeeding shown in some studies investigating clinical outcomes (Ickovics et al., 2007; Picklesimer, Billings, Hale, Blackhurst, & Covington-Kolb, 2012). They concluded that savings are harder to achieve in low-volume settings, and that actual savings would vary based upon the population cared for and organizational structure such as patient volume and the type of providers offering prenatal care (Mooney et al., 2008).

In 2001, Rising and associates, interested in the continued support and development of the Centering model, formed the Centering Pregnancy and

Parenting Association. The name was changed in 2006 from Centering Pregnancy and Parenting Association to the Centering Healthcare Institute, Inc. (CHI) to reflect the direction of the organization, whose mission is to improve maternal child health by transforming care through Centering groups (CHI, 2015b). As of 2012, CHI had developed facilitator-training, and teaching and learning materials for two types of group healthcare, CenteringPregnancy and CenteringParenting. In addition, CHI has instituted a site approval process that is aimed at supporting the organizational changes within healthcare organizations required to sustain the Centering model, insure model fidelity as it is adapted in each setting, and support ongoing research and evaluation (Centering Healthcare Institute [CHI], 2015c). On the CHI website, as of September, 2015 there were 343 clinical care locations that offered CenteringPregnancy and 143 of these sites had completed the CHI approval process (Centering Healthcare Institute [CHI], 2015a).

The Shared Medical Appointment model. The fourth and final model to be described is the Shared Medical Appointment (SMA) Model. Ed Noffsinger (2009) traced the origins of his first version of a shared medical appointment, the Drop-In Group Medical Appointment (DIGMA), to a personal experience. He had worked as a psychologist at Kaiser Permanente in San Jose and Santa Clara, CA for twenty years. In 1991, he became a patient with a life-threatening illness, and despite his “insider” status as a healthcare provider, he experienced frustration with poor access to care, short visits characterized by limited

communication with his providers, and a healthcare system that he described as not “patient-centered”. He described his care experience as one characterized by social isolation and various difficulties negotiating a complex, uncoordinated healthcare system that lacked ample therapeutic interactions with staff and providers (Noffsinger, 2009, pp. xxi - xxxi).

The focus of Noffsinger (2009) on improving access to care by providing timely (within a week), coordinated healthcare visits with a team of providers has continued to shape the development of the SMA model. His first group healthcare design, the Drop-In Medical Appointment (DIGMA), is described as including a random, heterogeneous group of 8–12 patients scheduled together for more timely or immediate care from a particular healthcare provider than could be possible with scheduling an individual appointment (Noffsinger, 2009). This group healthcare is described as occurring in a large room, with patients sitting in a circle of chairs, in which a nurse or medical assistant obtains vital signs, conducts brief health histories, helps with the scheduling of laboratory tests and other appointments or referrals, and assists the physician or other provider as needed. In a Shared Medical Appointment, a health behaviorist is the member of the healthcare team who focuses on facilitating the group educational and supportive discussions and a medical scribe is used to document the individual health histories, physical assessments, and medical decision making of the healthcare provider (Noffsinger, 2009).

Patient education and social support are recognized as important patient-centered components of the Shared Medical Appointment (SMA) as is the case in CenteringPregnancy and the other group healthcare models. However, as described by physicians with experience providing care from within the SMA model, the provision of patient education and social support seem to occur almost as a surprise bonus, rather than being seen as an essential element (Harvard Vanguard Medical Associates, 2011; Noffsinger, 2009).

Time and resource efficiencies of coordinated team care have been prioritized as major benefits of the SMA model, with the evidenced-based and patient-centered aspects of care less central to the model. The healthcare system benefits have been a very effective argument aimed at healthcare administrators and practice managers; leading to the spread of the SMA model into more diverse healthcare settings and patient populations than the Chronic Care Clinic and Cooperative Health Care Clinic models.

A second version of the SMA model of care was developed by Noffsinger (2009) for annual physicals, which he called the Physical Shared Medical Appointment (PSMA). This adapted version of the original SMA included many types of medical specialty group visits and pre- and post-operative surgical group visits. This latter approach provided for brief, private, individual physical examinations to occur in conjunction with the education and care coordination aspects of the group healthcare visit. Noffsinger recommended that groups be formed according to gender and age.

Noffsinger (2009) has written about the voluntary nature of group healthcare and has stressed the importance of inviting potential patients to participate by offering clear explanations about group healthcare and what it entails. As described by Noffsinger (2009), it is most often the responsibility of the behavioral health facilitator to state explicitly the rules of confidentiality and to obtain written/signed confidentiality agreements from all participants, including patients and their support people (p. 43). He offered other recommendations for respecting patient privacy such as providing the opportunity for a patient to have an individual visit with the physician as well as having the resources to conduct physical exams in private exam rooms separate from the group healthcare space (p. 143).

Group Healthcare Research

A growing body of research supports the adoption of group healthcare as an innovation that can succeed in improving select health outcomes. CenteringPregnancy, Chronic Care Clinic, and Cooperative Health Care Clinic models of group healthcare each have been studied with several randomized controlled trials (Beck et al., 1997; Coleman, E. A. et al., 1999; Coleman, E. A. et al., 2001; Ickovics et al., 2007; Ickovics et al., 2011; Kennedy et al., 2007; Scott et al., 2004; Wagner, E. H. et al., 2001). This body of research provides strong quantitative evidence for the effectiveness of group healthcare specific to the studied population. However, to date there have been no published RCT studies using the SMA model of group healthcare.

In the next section, the randomized controlled trials (RCTs) comparing group healthcare to individual care are described in more detail. A review of other research findings about the patient experience of group healthcare and the experience of privacy within group healthcare is provided. Finally, the implications of these studies for further research into the patient experience of privacy within the context of group healthcare are summarized.

Randomized clinical trial research: Group healthcare. Beck et al. (1997) conducted the first randomized trial of group healthcare in the United States. The study included 321 chronically ill, high-healthcare-utilizing adults age 65 and older in order to compare those attending Cooperative Health Care Clinics with usual care in a health maintenance organization. The study was conducted for one year. The patients randomized to group healthcare met monthly for two hours for each group session. The intervention group of patients attended an average of 6.62 groups. Individual visits were available as needed. Important to the validity of the findings, the analysis used intention-to-treat group assignments even though some of the intervention group patients did not attend any groups. Seventy-eight percent of patients who were initially recruited completed the study. There were similar rates of death or leaving the HMO for patients attending Cooperative Health Care Clinics and the individual-care patients. The care utilization cost estimate indicated that the intervention group care estimate produced an aggregate annual cost savings of \$14.79 per member per month. The savings were the result of significant positive outcomes for the

intervention group (those attending group visits). Positive outcomes included decreased number of visits to the emergency room, fewer repeat hospital admissions, fewer imaging tests, and higher rates of influenza and pneumonia vaccinations. No significant differences between the group-healthcare patients and individual-care patients were noted in terms of the number of laboratory tests ordered, number of prescription medications, use of visiting nurse services, lengths of hospital stays, hospital related charges, depression screening, or multiple measures of function (Beck et al., 1997).

Eric Coleman et al. (1999) conducted a 24-month trial of the Chronic Care Clinic model randomized within nine primary care practices. Frail older adults at high risk for hospitalization and functional decline were selected using a computer-based predictive index (p. 776). For each practice, the 36 patients with the highest risk scores using this index were selected. Physicians then removed their patients who were too ill to participate. A total of 169 elderly patients (>65 years old) without dementia or severe hearing loss were invited to participate in the study and then randomized to either group or individual care. Ninety-six patients participated in the Chronic Care Clinic model of group healthcare over the two-year period of the study. Outcome measures were self-reported by patient response to questionnaires. Medication prescription and service utilization data were abstracted from medical records. The researchers found no difference between individual care and Chronic Care Clinic group healthcare on outcome measures of incontinence, falls, depression screening, or physical function. Costs

as assessed by hospitalizations, emergency room use, and frequency of visits were similar in each group. Of interest is that 40% of patients randomized to Chronic Care Clinic group healthcare rated the overall quality of the medical care they received as excellent in comparison to 25.3% of patients receiving usual care. Coleman, E. A. et al. (1999) concluded that system-wide support beyond that offered in the Chronic Care Clinic model is needed to improve geriatric care.

E. H. Wagner et al. (2001) subsequently conducted a system-wide randomized trial of the Chronic Care Clinic model of group healthcare focused on patients with diabetes over 30 years of age receiving care in an HMO in Seattle, WA. The researchers randomized practice groups of family physicians to intervention or usual care. Patients within each practice who were identified through a diabetic registry were then invited to participate in the study. Questionnaires were mailed to patients at the beginning of the study. Of 1001 eligible patients, 707 completed the initial questionnaire. Follow-up questionnaires were distributed at twelve months and 24 months and follow-up phone call interviews were conducted for those not returning the mailed questionnaires. Similar numbers of patients in both groups died during the study, although the actual numbers were not reported in the published report. Of the surviving patients, 87% ($n=278$) of those participating in the group healthcare intervention completed the study and 79% ($n= 429$) of usual care patients completed the study. An intention-to-treat analysis was used.

The findings of E. H. Wagner et al. (2001) included a positive association between the number of group sessions attended, higher patient satisfaction with care, and lowered HgbA1C screening results. At 24 months, the intervention group had received significantly more of the recommended preventive procedures for diabetic care - medication review, foot exams, and retinal exams. Patients attending more Chronic Care Clinic sessions rated the use and helpfulness of their patient education experiences more highly than control patients. The intervention group had a mean number of one more ambulatory visits per year and one less specialty visit per year.

E. H. Wagner et al. noted that this study was conducted during a time of significant change in the HMO that created challenges to a consistent implementation of team care in the context of a decrease in nursing staff. The researchers reported that 35% ($n=278$) of the intervention group never attended a group session. They suggested that the positive effects of group healthcare might have been greater than evidenced in the study's findings given this situation. Strengths of the research were the inclusion of patients and practice settings similar to the real world in contrast to the self-selected highly motivated patients and clinicians who usually participate in randomized controlled trials.

Scott et al. (2004) conducted a two-year prospective, randomized controlled trial of the effectiveness of the Cooperative Health Care Clinic model of group healthcare, building upon the previous study published by Beck et al. (1997). Patients selected for randomization were over 60 years old, had 11 or

more outpatient visits in the prior 18 months, had one or more chronic conditions, and expressed an interest in receiving group care. Two hundred and ninety-four patients were included in the study. All patients completed an initial survey that included self-assessments of health and functional status and patient satisfaction. A similar survey was repeated at 24 months. Administrative data for utilization and cost were collected retrospectively for 12 months before the study began and continued during the 24-month study period. The intervention patients attended an average of 10.6 sessions over the 24-month period, with a wide range of attendance. Almost a quarter of the intervention group ($n=145$) attended two or fewer group sessions. There were significantly fewer hospitalizations and emergency room visits in the intervention group in comparison to the usual care group ($n=149$). No difference in health or functional status change was demonstrated. However, patients participating in the Cooperative Health Care Clinic groups reported increased patient satisfaction and self-efficacy for communication with their physicians.

There are two randomized control trials of group visits for patients with diabetes that have played an important role in building evidence supporting group healthcare, despite the fact that the groups studied are outside the criteria used to define group healthcare in the Patient Experience of Privacy in Group Healthcare Study. In the two reports by Trento et al. (2001, 2004), medical care for patients with diabetes occurred during individual visits, with the groups used to educate, coordinate care, and provide social support to diabetic patients.

Trento et al. (2001; 2004) conducted a randomized control trial over a five-year period in Italy. The findings from the first two years of the study were published in 2001. This study enrolled 112 type 2 diabetic patients, both men and women, randomized to the group intervention ($n=56$) or usual individual-care ($n=56$). All patients continued to receive individual care and the physicians providing the medical care to these patients were blinded to their group assignment. The two year findings (Trento et al., 2001) included an analysis of HgbA1c that found that patients in the individual-care situation had HgbA1c levels that rose in comparison to the stable values for patients in the group-intervention. Also, during the first two years of the study, two of the patients in the group-intervention required the addition of insulin to their care regimen, compared with five patients in the individual-care group. Better glucose control for the group-intervention patients as compared with the individual-care patients was suggested by these findings. Group care patients increased their adoption of more appropriate health behaviors as measured by a 16 item *Condotta di Riferimento* [CdR] questionnaire compared to a decrease among the individual-care group. The group intervention patients initially reported lower knowledge about diabetes and self-care as measured by the GISED³. Their knowledge increased as evidenced by a statistically significant change in mean scores from

³ GISED is a 38-item questionnaire developed by the Education Study Group of the Italian Society for Diabetes (Trento et al., 2004, p. 672)

14.9 to 24.0 compared to the individual-care group mean GISED scores of 20.1 that dropped to 17.4.

Outcomes reported for the five-year study included continued improvement in measures of HgbA1c for the intervention group-care patients, but no change in the individual-care patients. Other clinical outcomes such as body mass index, lipid profiles, and creatinine levels improved for both groups. Measures of quality-of-life showed improvement at the two-year measurement for the intervention group (Trento et al., 2001). These improvements in quality-of-life were retained at the five-year measurement (Trento et al., 2004). In contrast, quality-of-life diminished over the course of the study for patients in the individual-care group. In a similar pattern, knowledge about diabetes care as measured by the GISED questionnaire increased continuously for the patients with diabetes in the group-care intervention while knowledge gradually decreased for patients in the individual-care group.

This body of research, including the positive findings of Sadur et al. (1999) and E. H. Wagner et al. (2001), provided evidence supporting the use of group healthcare for diabetic patients. Recently published descriptions of the implementation of group healthcare for diabetic patients include Kirsh et al. (2012). They detailed the use of Shared Medical Appointments to “improve care for high risk patients and maximize provider expertise”. Watts et al. (2015) reported improvements in HgbA1c levels for 90.7% of the 1290 patients attending one or more Shared Medical Appointments for patients with diabetes. This study

was conducted over a four-and-a-half-year time period at a Veteran's Administration health center using a retrospective pretest/posttest design.

In a review article, Weinger (2003) proposed a typology of models of group medical visits. The models included in the typology have demonstrated clinical outcome benefits for patients with diabetes. The research studies included in the review were reflective of care provided using group healthcare approaches or models – education-based cluster visits (Sadur et al., 1999), Chronic Care Clinic (Wagner, E. H. et al., 2001; Coleman, K., Matke, Perrault, & Wagner, E. H., 2009), Cooperative Health Care Clinic (Beck et al., 1997; Coleman, E. A. et al., 2001), and Shared Medical Appointment models (Noffsinger & Atkins, 2001). The review highlighted the difficulty in comparing the varied models. Yet, the positive findings from the research reviewed in the article led the author to call for a more systematic description of model components to advance knowledge about the usefulness, practicality, and effectiveness of these models of group healthcare.

In a qualitative review of group healthcare research Jaber, Braksmajer, and Trilling (2005) emphasized the difficulty inherent in comparing research studies that used various models of group healthcare for diverse populations while measuring a broad range of outcomes. They suggested abandoning old nomenclature related to the origins of these models of group healthcare and called for clearer definitions of the structure, processes of care, content of visits, and commonly used and appropriate outcome measures in subsequent research about group healthcare. These two review articles of group healthcare by Weinger

(2003) and Jaber et al. (2005) focused on primary care for patients with chronic illnesses and therefore excluded research into the CenteringPregnancy model through this review criterion.

Kennedy et al. (2011) conducted a randomized clinical trial of the CenteringPregnancy model of group care to examine the feasibility of this model of care for women receiving prenatal care in the military health system. Three hundred and ten women receiving prenatal care at two US military hospitals who agreed to participate in the study were randomly assigned to group or individual care. The groups were similar on demographic variables. Multiple perinatal outcomes were measured through review of the electronic medical records including gestational age at birth, mode of delivery, and birth weights. Findings indicated that there was no difference in preterm births or neonatal intensive care admissions between the group prenatal care and individual-care women. Satisfaction with care was measured by the Patient Participation and Satisfaction Questionnaire, a tool developed by the investigators. In addition, in-depth, open-ended interviews were conducted to assess patient experiences of healthcare. Compared with women receiving individual care, women receiving group prenatal care reported higher satisfaction with the quality of care and an appreciation for provider continuity, education, and group support. The researchers concluded that the CenteringPregnancy model could meet the prenatal care needs of military families. CenteringPregnancy has subsequently been

successfully adopted in at least three military healthcare settings (Foster et al., 2012).

Ickovics et al. (2007) conducted a prospective, multi-site, randomized controlled trial of the CenteringPregnancy model of group healthcare at two inner-city hospital-based clinics. This study built upon positive findings of a previous prospective matched cohort study of 458 women receiving usual and group prenatal care in the same settings (Ickovics et al., 2003). Pregnant women aged 14 - 25 years who enrolled for prenatal care prior to 20 weeks of pregnancy were recruited. In total, 1047 women were randomized to receive usual or group prenatal care with 993 women completing the study. An intention-to-treat analysis was maintained. Eighty percent of the women participating in the study were African American. The mean age of the study participants was twenty.

The study was designed to test changes and differences in risky sexual behaviors and sexually transmitted infections. Improvements in perinatal health outcomes were part of a secondary data analysis. The rate of preterm birth among the women participating in group healthcare was 9.8% compared with 13.8% in the usual care group, which although not statistically significant, was equivalent to a risk reduction of 33% (odds ratio 0.67, 95% confidence interval 0.44-0.99, $P=0.45$) (Ickovics et al., 2007). This effect was even stronger among the African-American women participating in group care. For African-American women, the results indicated a 10% preterm birth rate in the group healthcare condition compared to 15.8% for women in the usual care group (OR 0.59, 95% CI 0.38-

0.92 $P=.02$). Women in the intervention group also demonstrated an increase in measures of knowledge about pregnancy, readiness for birth, and a greater satisfaction with care, although the tool the researchers developed to measure pregnancy knowledge was not validated (p. 335). Furthermore, the researchers found that breastfeeding was initiated at a higher rate for women participating in group care (66.5%, $n=623$) vs. the women in the usual care group (54.6%, $n=379$). The researchers recommended replication of the research among other populations of patients and in other settings. They postulated that the group experience of social support and empowerment might provide a reduction of stress contributing to the observed improvement in clinical outcomes for the women receiving group healthcare. Further research was recommended to investigate mechanisms of action.

An additional analysis of data from the same group of 1047 pregnant young women examined the effects of group prenatal care on measures of psychosocial risk (Ickovics et al., 2011). The findings from this analysis were based on self-administered audio CASI* interviews by pregnant women themselves prior to 24 weeks of pregnancy, again in the 3rd trimester of pregnancy, and at 6 months and 12 months after birth. Stress was measured using the widely used reliable and valid Perceived Stress Scale, self-esteem was measured using the validated Rosenberg Self-Esteem Scale, and social support

* CASI is a computer based system that includes both written and audible questions and responses supporting the participation of low-literacy respondents.

and social conflict were measured using subscales of the Social Relationship Scale, and depression was measured with the affect only part of the widely used CES-D (p. 239-240).

There were differences between the group-care and individual-care groups of study participants for the factors of race, health behaviors, and self-esteem at the baseline assessments (Ickovics et al., 2011). These factors were statistically controlled in subsequent data analyses. There were no significant differences in the psychosocial outcomes measured over time between types of care for the women. Stress declined in the postpartum period for all participants, validating that the experience of pregnancy is a significant stressor for the low-income, predominantly African American young women in the study.

A sub-group analysis of women reporting the highest levels of stress at baseline assessment suggested improved outcomes relative to self-esteem and stress during the third trimester of pregnancy for women in group prenatal care (Ickovics et al., 2011). However, this difference did not persist at the six- and 12-month postpartum period. The high stress sub-group of women receiving group prenatal care also had decreased social conflict and depression compared with women in the usual care group, and these changes persisted when measured at the end of the study period, 12 months after birth. Based on these findings, Ickovics et al. (2011) recommended additional research into improving ways to identify women who are at most risk for poor psychosocial outcomes related to stressors present during pregnancy. In addition, they called for further investigation into

the mechanisms linking improved biological outcomes with positive changes in psychosocial measures evidenced in women participating in group healthcare.

Both of the randomized trials reported by Ickovics et al. (2007) and that of Kennedy et al. (2011) used as a foundation earlier exploratory studies suggesting positive clinical and patient experience outcomes, including those of Grady and Bloom (2004); Massey, Rising, and Ickovics (2006); and Baldwin (2006). A small quasi-experimental study by Robertson et al., (2009) used a two-group comparison of 49 pregnant Hispanic women who self-selected into group healthcare or usual care. Study questionnaires were completed at entry into the study (no later than 26-weeks gestation), in the third trimester, and postpartum, although the duration of time after birth was not reported. The women in the group prenatal care were more likely to be first-time mothers. Only 33 participants completed the final postpartum interview. Measures included in this study were the Pregnancy History Scale and Rosenberg Self-Esteem Scale at entry into the study. At 34 to 36-week gestation participants completed Prenatal/Postnatal Care Knowledge and Pregnancy Relevant Health Behaviors questionnaire. At the postpartum evaluation women completed the Breastfeeding Behavior Scale, Rosenberg Self-Esteem Scale, Center for Epidemiology Depression Scale and Patient Participation and Satisfaction questionnaire. There were no differences in pregnancy outcomes, breastfeeding experience, satisfaction with care, and depression scores for women participating in group prenatal care compared with women receiving individual prenatal care. Although failing to

demonstrate differences in the measured outcomes between the two groups, the researchers concluded that the CenteringPregnancy model provided care comparable to usual care as evidenced by similar clinical outcomes and patient satisfaction with care.

Picklesimer et al. (2012) focused on the outcome of premature birth in a low-income group of pregnant women in South Carolina. Using a retrospective cohort design, they included 316 women classified as low-obstetrical-risk receiving CenteringPregnancy group prenatal healthcare compared with 3767 pregnant women receiving usual care. Both intervention and control groups were racially diverse with slightly different distributions that were controlled for in the data. Of women participating in group care ($n=316$), 34% were White, 34% were Black, 17% were Hispanic and 15% were Other. This compares with the women receiving traditional care ($n=3767$) with 46% White, 26% Black, 22% Hispanic and 7% Other.

Preterm deliveries, defined as birth at less than 37 weeks completed gestation, were significantly fewer the group care intervention with 7.9% vs. 12.7%, $P=.01$ and an adjusted odds ratio for preterm birth of 0.53 (95% confidence interval, 0.34 - 0.81) (Picklesimer et al., 2012). Very premature deliveries, defined as birth at less than 32-week gestations were also significantly fewer for the intervention group with 1.3% vs. 3.1%; $P = .03$. The group-care cohort in this study was younger, more likely to be minority, and included more

nulliparous women, all of which theoretically would have increased the risk for preterm birth, making the study finding more robust.

Barr, Aslam, and Levin (2011) also reported a trend toward a lower rate of preterm birth among women receiving group prenatal care in their retrospective cohort study evaluating pre- and post-implementation of CenteringPregnancy into the obstetrical training curriculum of a family practice residency. The clinical outcomes for 184 women receiving usual prenatal care (prior to instituting the CenteringPregnancy model) from medical residents supervised by nurse-midwives were compared with those of 195 women receiving care from teams of nurse-midwives and family practice residents using the CenteringPregnancy model. The CenteringPregnancy group had a lower rate of preterm birth (4.15% vs. 8.33%). The researchers reported improvements in all process-of-care outcomes as evaluated using IMPLICIT quality improvement measures, including screening for smoking and depression. Specifics of the IMPLICIT patient satisfaction measures were not included in the article. The authors theorize that improved resident counseling skills – listening, teaching and offering support – learned during the experience of providing care using the CenteringPregnancy model “impacted how residents viewed and treated all of their patients” (p. 715). More information about the patients’ viewpoints on receiving group prenatal care and about the resident’s experiences offering group prenatal care might provide evidence to evaluate the authors theoretical explanation for their findings.

There have been three articles reviewing research about CenteringPregnancy. Manant & Dodgeson (2011) included 26 articles (14 narrative descriptions, and 12 data-based research) studies in their integrative literature review. They noted that inconsistencies in defining and measuring outcomes limited the ability to compare findings. They called for more qualitative studies into the effects of participation in group prenatal care to develop more useful outcome variables.

Sheeder, Yorga, and Kabir-Greher (2012) reviewed eleven CenteringPregnancy articles including descriptive, cross-sectional, cohort, and randomized controlled studies. They concluded that CenteringPregnancy showed promise in improving participant satisfaction when compared to individual visits. However, they cautioned that the studies that suggested improved clinical outcomes were conducted among 20-to-25-year-old women of low socioeconomic status and may not be generalizable to other populations.

Tilden, Hersh, Emeis, Weinstein, and Caughey (2014) reviewed and compared outcome data from 10 studies they determined to have strong designs or large sample sizes. Based on their evaluation of these studies, they cautioned against research that conceptualizes a ‘dose response’ - the more group care the better the clinical outcome. Rather, they called for further research that considers the possibility that “the positive outcomes associated with group prenatal care are related to variables that have not yet been defined or quantified” (p. 52).

Descriptive and qualitative research findings: Group healthcare.

Most research into group healthcare that has measured effects on clinical outcomes also included the evaluation of patient satisfaction, but the reports of findings rarely included details of how patient satisfaction was assessed. Often simple questions like “Would you recommend group care to a friend or family member?” or “Would you choose group or individual care for your next visit?” are the only assessment of patient satisfaction. While these questions may be valid measures for comparing different approaches to care, they provided little insight and details about patient perceptions and experiences of their care.

Greater details about patient experience and satisfaction have been included in some descriptive reports and in qualitative studies of group healthcare. For example, in a qualitative study to assess the feasibility of group care for low-income women with chronic disease, Miller, Zantop, Hammer, Faust, & Grumbach (2004) interviewed 28 women participating in a trial of group medical visits. As included in their findings, several concerns were expressed by the women in their study related to their experience of care in a group setting. Women in their study described difficulty in supporting others women in the group as well as concerns about confidentiality. With regard to the experience of privacy in group healthcare, the authors commented, “relatively few participants mentioned concerns about breaches in privacy. This may be because the facilitators set confidentiality group rules in the first group visit” (p. 223).

The literature indicated that the practice of verbal and written review of confidentiality is included in the “how to” descriptions of all four models of group healthcare (Noffsinger, 2009; Bartley & Haney, 2010; Group Health Cooperative, 2001; Rising, 1998). Authors of some of the qualitative studies have suggested that while this formal process of addressing confidentiality provided some reassurance about the intent and responsibilities of group healthcare providers to protect confidentiality and respect patient privacy, it neither guaranteed absolute confidentiality nor ensured a sense of trust that might enable group participants to choose to share personal information within the group.

The CenteringPregnancy model of care has been the setting for multiple qualitative investigations into the experiences of pregnant women and of providers with this model of group healthcare. Kennedy et al. (2009) interviewed women who had been part of a randomized clinical trial comparing usual care with CenteringPregnancy three months after birth to better understand their experience of prenatal care. They were interested in obtaining women’s experiences and perceptions about what they liked most and least and what they would change about their experience. Of the 322 women enrolled in the study, 73% completed the final three-month postpartum interview. A thematic analysis of the interview data was conducted. The authors presented three overarching themes resulting from their analysis. The themes they presented were:

1. “I wasn’t alone” -- the experience with group prenatal care
2. “I liked it but...” – recommendations to improve group prenatal care

3. “They really need to listen” – general concerns across the sample about their childbearing care (p. 178).

Privacy concerns factored significantly in the issues raised by women as they reflected on improving group care. Suggestions by the women noted by the researchers included increasing physical privacy and adding occasional individual care visits. Additionally, some women expressed discomfort about the involvement of male partners in the groups sessions. These findings highlighted the need for healthcare providers to listen more closely to the patient experience of privacy in order to include the patient’s voice when adapting existing models to address concerns related to confidentiality and privacy in group healthcare.

Three analyses by Novick et al. provided an in-depth description of women’s experience of group prenatal care using data generated by her longitudinal ethnographic research (Novick et al., 2011). The first study involved an analysis of the intersections of the complexity of everyday life situations of women and their experiences of prenatal care (Novick, Sadler, Knafl, & Groce, 2012). A second study explored the experiences of midwives providing group prenatal care in two urban clinics (Novick, Sadler, Knafl, Groce, & Kennedy, 2012). Data collection methods used in this research included individual, in-depth semi-structured interviews with 21 low-income minority women during pregnancy and after birth; interviews with two certified nurse-midwife and two medical assistant group leaders; participant observations of four series of group

prenatal sessions and; a medical record review. The third analysis examined the relationship between model fidelity and outcomes (Novick et al., 2013).

The central finding of Novick et al. (2011) about women's experience of group prenatal care was that women enjoyed receiving their care in groups (2011). The researchers described how women's participation in discussions within group healthcare and the types of discussions in each group evolved over time. For example, the authors noted "some intimate topics such as vaginal discharge or sex during pregnancy arose early on in the group process" and that this sharing of the common discomforts of pregnancy in early groups lead to later sharing of more intimate feelings (p. 101). However, women's participation in group discussions and how the women felt about the participation of family members and partners varied widely. Some women who were observed to be very quiet expressed enthusiasm for group care during the individual interviews. Novick et al. (2011) concluded "many women had entered prenatal care while experiencing profoundly difficult personal situations, but these were rarely discussed in the groups" (p. 102) indicating that women made choices not to disclose personal information of a sensitive nature.

This latter finding by Novick et al. among low-income women differed from other descriptions found in the literature of primarily positive support and personal sharing by women in group care (Kennedy et al., 2009; Herman, Rogers, & Ehrenthal, 2012). The finding suggested that the group healthcare experiences of privacy may be more complex and nuanced than that offered by a simple,

positive evaluation of participation in group care. The researchers posited several explanations for women choosing to keep personal information private. Perhaps a choice to forgo disclosure indicated that women felt empowered not to participate in a discussion or share private matters with the group. The findings highlighted one aspect of privacy - namely, the right to be silent or protect one's personal information. On the other hand, it could be that trust in the confidentiality and safety in the group was not great enough to allow for sharing of risky personal information.

The balance between disclosure and maintaining privacy exists in every provider-patient encounter. However, a group setting can be seen as presenting a greater complexity of relationships for patients to navigate. Novick et al. (2011) presented a theme centered around women's relationships with boundaries in group healthcare. They commented, "one woman refrained from discussing disturbing topics because she worried that it might 'depress' other pregnant women" (p. 105).

Included within the theme of boundaries, the group facilitators' setting of clear boundaries was important in facilitating discussions of sensitive topics. Setting boundaries also was reflected in statements made by the women in the Novick et al. (2011) research about physical privacy. Many women in their research described initially feeling embarrassed by sensitive topics or experiences of bodily functions or personal problems such as domestic violence, substance abuse, or homelessness. Even though the researchers found that women became

more comfortable with discussions of bodily changes experienced or anticipated during pregnancy, birth, and new motherhood, they also found that significant personal problems were rarely disclosed within the group (p. 106). With regard to physical examination within the group space, women in their research described a broad spectrum of comfort, sometimes related to the presence of male partners in the group. Women also varied in their willingness to participate as live models for demonstrating some aspects of care for the group, such as modeling certain positions for labor and birth (p. 107).

Another common finding of both Novick et al. (2011; 2012) and Kennedy et al. (2009) involved women's reporting of wishing for greater privacy during physical exams and more personal private time with providers on occasion. Novick et al. (2011) underscored that "because integrating physical care with education and support is so central to this approach, differentiating group prenatal care from both conventional prenatal care and childbirth education classes, it is critical to fully understand and address these privacy needs" (p. 111).

Despite some negative experiences regarding privacy concerns, the positive benefits from sharing personal feelings about the pregnancy experience was a robust qualitative finding in all of Novick et al. (2011; 2012; 2013) analyses and the qualitative study conducted by Kennedy et al. (2009). For example, women were "delighted and often surprised" to discover they were not alone in their experiences of pregnancy (Kennedy et al., 2009, p. 179).

McNeil et al. (2012) conducted a qualitative study using a phenomenological approach in which they interviewed one-on-one eight women and five women in a validation session all of whom had attended CenteringPregnancy groups. The CenteringPregnancy groups were facilitated by a family practice physician and perinatal educator in Alberta, Canada. The analysis of McNeil et al. identified 'Getting more than they realized they needed' as the core experience, based on six themes. They did not mention of privacy or confidentiality within their discussion of any of these themes.

Phillippi and Myers (2013) interviewed 29 women who had declined CenteringPregnancy in a rural birth center in southern Appalachia to explore their reasons for preferring individual care. Findings included an expressed preference by the women in their study for one-to-one care based on a dislike of groups and fear of emotional and physical exposure. Privacy was expressed as a prime concern and included "disdain of displaying or discussing their body, privacy, fear of emotional breakdown, and distrust of disclosing private information" (p. 519). The authors noted the similarities of their findings with that of Novick et al. (2011) and recommended further research to determine how extensive these privacy concerns are in other populations of women.

Herrman et al. (2012) conducted a small focus group study with 33 women participating in the CenteringPregnancy model of group prenatal care that focused on women's perceptions of the strengths and weaknesses of the group prenatal care models as well as areas for improvement. Privacy concerns were

featured within several of the thematic categories that emerged in their analysis. They included women's discussions of how some mothers do not like the group nature of CenteringPregnancy due to discomfort with the inclusion of partners and a lack of privacy (p. 21).

Summary

In summary, the quantitative and qualitative study findings described in this chapter suggested that further investigation into the patient experience of privacy while participating in group healthcare was required to understand better the phenomenon of privacy and patient needs that may not be addressed completely by current models of group healthcare. Increasing our understanding through the development of knowledge about privacy experiences in the specific context of CenteringPregnancy has the potential to improve methods of recruiting women for group healthcare by providing evidence-based approaches to privacy protection and offering the best care possible. Researchers have called for studies that will advance knowledge about group healthcare processes and outcomes in order to provide direction for improvement in group healthcare visits.

The growing body of quantitative research reviewed indicated that group healthcare has demonstrated modest positive clinical outcomes, high levels of patient satisfaction, and the potential to decrease costs. The literature has included a description of a variety of positive and negative patient experiences with physical care in a group healthcare space, personal disclosures, and the confidentiality of information shared within the group. However, a knowledge

gap exists about the phenomenon of privacy as experienced and conceptualized by women who participated in CenteringPregnancy group healthcare. The literature indicated that group healthcare presented challenges to one's sense of privacy provided by individual visits. An in-depth understanding of privacy as experienced and conceptualized by patients in the context of group healthcare is foundational for advancing our understanding of patient privacy and enhancing clinician's efforts to provide holistic and patient-centered ethical healthcare.

Chapter Three: Method

The Patient Experience of Privacy While Participating in Group Healthcare study was conducted using a qualitative research design named descriptive phenomenography. This research focused on developing a conceptualization of privacy within the context of Centering Pregnancy as a particular model of group healthcare. This phenomenographic research study specifically focused on the researcher's development of an in-depth description of participant's experiences and conceptualizations of privacy as reflected upon during individual interviews with women who had participated in CenteringPregnancy group healthcare. This research study provided answers to the following research questions:

1. What is the privacy experience of women who participate in the CenteringPregnancy model of group healthcare?
2. How does the patient experience of privacy in a group healthcare care setting differ from the experience of privacy as experienced during individual care?

For the purposes of this study, it was assumed that the patients chose to obtain group healthcare were well accustomed to the individual exam room and patient-provider experiences typical of usual care in the United States. It turned out that three of the study participants had also experienced healthcare in other countries. Given this diversity of experience, these three women could be relied upon to speak about how their experience of group healthcare differed from their

experience of individual care from a broader perspective that included healthcare outside the US. All fifteen women were expected to be able to speak about their experiences in both positive and negative ways.

The remainder of Chapter 3 provides an overview of the qualitative design of phenomenography, the rationale for choosing this approach for the description of the experience and conceptualization of privacy within the context of CenteringPregnancy, the study setting, the recruitment of study participants, data collection, data analysis, and qualitative rigor.

Qualitative Design: Phenomenography

Phenomenography was developed to provide a qualitative methodology useful for studying phenomena from multiple perspectives. It provides the qualitative researcher with an approach to explore the ways in which human interactions contribute to the generation of complex phenomena like the experience, conceptualization, and meanings of privacy (Richardson, 1999).

Phenomenography was developed in the 1980s by Ference Marton (1981). Marton was an educational researcher who used the phenomenographic approach to investigate the process of learning and knowing from the perspective of students. Since its development, phenomenography has continued to be applied in the field of education (van Rossum & Hamer, 2010). As a qualitative research approach, it has yielded rich qualitative findings that have informed both the theory and practice of teaching and learning (van Rossum & Hamer, 2010). However, phenomenography has been used in healthcare research in a limited

manner, particularly in the areas of the education of healthcare professionals, patient education, and patient experiences of healthcare (Larsson & Holmström, 2007; Stenfors-Hayes, Hult, & Dahlgren, 2013).

Philosophical foundations of Phenomenography. Phenomenography, as a qualitative research approach, is supported and grounded in the philosophical roots of phenomenology (van Rossum & Hamer, 2010). In phenomenological research various modes of being human are disclosed (Lopez & Willis, 2004; van Manen, 1990). Phenomenologist and educator Max van Manen (1990) described phenomenology as a research approach for the study of human beings' lived experiences. According to van Manen, the study of lived experience involved grasping the meaning of the individual's lifeworld (the world of lived experience) as experienced rather than as conceptualized, categorized or theorized.

Phenomenology, as a research approach has been widely used in nursing research and adapted to the goals and aims of both descriptive and hermeneutic nursing science (Lopez & Willis, 2004). Fundamentally, nurse researchers utilizing descriptive and hermeneutic phenomenology aim for a deeper understanding of the nature or meaning of everyday lived experiences of human beings in various health and illness situations via a focus on the human lifeworld (Lopez & Willis, 2004).

A philosophical ground of the phenomenological approach that van Manen (1990) emphasized is for the researcher to understand and reveal the ways in which the meaning of human beings' lived experience is created through their

ties to the larger human world. This focus on human beings' ties to the larger human world in phenomenological research reflected the individual's participation in the cultural, social and historical contexts of the world comprising a relational view of persons (Lopez & Willis, 2004; Munhall, 2012). Most importantly, researchers using a phenomenological research approach intentionally sought to understand the subjective lived experience of human beings, treating the individuals involved in phenomenological research not as objects of study, but rather as participants in a shared exploration and investigation of lived experience through the dialogue of the interview and reflection. Nursing researcher Munhall (2012) preferred the use of 'phenomenological approach' rather than 'method' in order to "embrace the possibilities of thinking and being phenomenological from one's perspective toward living and being" (p. 117).

Marton (1996) defined phenomenography as a research approach that incorporated a holistic, contextualized, non-judgmental orientation to generating an understanding of individuals' subjective ways of knowing or conceptualizing. What best distinguished phenomenography from phenomenology is its focus on what Marton called 'second level experience and knowing' (or conceptualization and meaning) of phenomena rather than first level experience (direct sensual perceptive experience) (p. 172-177). In practice, the distinction between phenomenology and phenomenography is not a sharp line, but rather one of degree or emphasis by the researcher. It is common practice when qualitative

researchers interview people about their experiences to find that the interviewees will entwine both levels of experience together in describing and discussing events in their past. Thus, the explicit focus of the interviewer on participants' ways of conceptualizing and experiencing in phenomenography shapes and defines the distinction between the phenomenological and phenomenographic approaches.

Similar to phenomenology (Lopez & Willis, 2004; van Manen, 1990) the philosophical underpinnings, goals and findings of phenomenography can range from descriptive to interpretive. Both approaches are most rigorous when the underlying assumptions, philosophical groundings, and researcher's point of view are clearly stated and congruent throughout the study, from design element to reporting (Dall'Alba & Hasselgren, 1996; Lopez & Willis, 2004). The product or outcome of phenomenography can also be similar to a grounded theory product as phenomenographic outcomes move towards higher level concepts, and in some cases, developmental theories, for example in the work of Marton (1996) or van Rossum and Hamer (2010).

Phenomenographic and phenomenological research are philosophically congruent. However, phenomenographic research is different in its aim, approach, and analysis from phenomenological research. For example, phenomenological researchers focus their attention on a human being's lifeworld as experienced rather than as conceptualized or categorized. Whereas, phenomenographical researchers focus their primary attention on an individual's

ways of knowing, conceptualizing, and understanding concepts (e.g. privacy) and how individuals categorize or make meaning out their experiences by using these concepts. In the end, the general purpose of phenomenographic research is to develop full descriptions and conceptualizations of human experience that are depicted in outcome maps that are the products of phenomenographic research. For this phenomenographic research, the topic of inquiry was multiple individuals' conceptualizations of the phenomenon of privacy, including their experiences, understandings, concepts, perceptions, and personal meanings.

Given the central role of language in phenomenographic research and the role of language in communication about human experiences, this phenomenographic research investigation of privacy included a focus on the language of participants (qualitative interview data). The qualitative data generated through interviews with women about privacy who had participated in CenteringPregnancy group healthcare were assumed to be recollected and retold memories about what they felt and thought about in particular situations. Thus, the researcher explored how the women conceptualized and understood their experience of privacy. Furthermore, based on the assumption that privacy was a complex socially and psychologically constructed concept, the qualitative interviews for this study focused on eliciting subjects' descriptions of their conceptualizations and experiences of privacy while participating in group healthcare. Through an exploration and analysis of the data generated from these interviews, the various conceptualizations the interviewees drew upon in giving

voice to their experiences of privacy as well as how they made meaning of privacy was revealed.

In summary, phenomenography was designed to generate varied understandings or conceptions of a particular phenomenon by incorporating the subjective experiences and conceptualizations of individuals into the organizing contexts of varied worldviews (Mazer, 2011). Thus, the Patient Experience of Privacy While Participating in Group Healthcare study was designed and conducted as a descriptive phenomenography with the researcher committed to an analysis that retained the individual voices of the study participants.

Rationale for Descriptive Phenomenography. The first rationale for using a phenomenographic research approach in nursing and healthcare research rests on the importance of generating a fuller conceptual understanding about concepts that address and bring forward the unique experiences, knowing, and perceptions of individual patients, giving voice to what matters to them and their frames of reference. The resulting understanding can then be organized and analyzed in a manner that becomes applicable to broader realms of care such as practice, education, and policy (Sjöström & Dahlgren, 2002; Mazer, 2012). Qualitative research that enhances provider understanding of individual patient experience is significant. Qualitative health research matters because patients tell us it matters (Munhall, 2012). Such research can enhance our ethical responsibility as providers to respond to patients' needs and concerns with compassion and empathy (Munhall, 2012).

Another rationale for using phenomenographic research is the capacity afforded the researcher using this approach to examine conceptualizations of power and issues of power imbalances within the contexts of patient experiences (Widäng, Fridlund, & Mårtensson, 2007). For example, The Centering and Cooperative Health Care Clinic models are most explicit about empowering patients through education, engaging patients' participation in self-management and attempting to change the power differential between patients and providers. In addition, empowerment (Klima, Vonderheid, & Norr, 2007) and engagement (Barello, Graffigna, & Vegni, 2012) as well as the concept of privacy are difficult to measure. However, conceptual measurement difficulties do not imply a lack of influence upon clinical outcomes. Thus, a qualitative exploration and investigation of privacy as experienced in group healthcare, and other associated concepts (empowerment and engagement) from the patients' point of view, may further understanding of the ways in which these concepts are interrelated. For example, Novick's longitudinal ethnographic methodology helped to reveal more complex data than interview or observation alone would have collected, validating positive and negative aspects of CenteringPregnancy through the experiences and voices of the women receiving group prenatal care (Novick et al., 2011; 2012).

The final rationale for using a phenomenographic approach to explore and describe patient experience of privacy in CenteringPregnancy is the match between the research approach and the manner in which this model of group

healthcare explicitly acknowledges the personal and cultural components of pregnancy, becoming a parent, learning new self-management skills, and changing health behaviors. Phenomenography was developed to enable researchers to account for the conceptualizations and experiences of patients in a manner that encompasses more than the medical diagnosis or medical needs of patients that brought them into the healthcare system (Sjöström & Dahlgren, 2002). Phenomenographic research has included both interview and observational techniques, rooted in the qualitative traditions of ethnography (Fetterman, 1998), sociology (Denzin & Lincoln, 2005) and psychology (Hennink, Hutter, & Bailey, 2011), as necessary to develop full conceptualizations and outcome maps that are the products of phenomenographic research. These research disciplines, when utilizing qualitative approaches to knowledge development, approach research subjects/participants as valid knowers of their experiences. The researcher for this phenomenographic study of privacy as conceptualized and experienced by women who had participated in CenteringPregnancy group healthcare assumed that their subjective experiences could be explored and understood within the context of their healthcare and the cultural and social world in which they were engaged.

The Researcher's Professional Background

The researcher conducting this research study is a practicing certified nurse-midwife. The Healthcare Practice has employed her for the past 10 years, as a hospitalist on a collaborative midwifery and obstetrical team providing

maternity care at a suburban hospital. It is important to note that the patients from the Healthcare Practice office sites where the researcher provides maternity care were not included in the study to prevent blurring of the researcher and clinician roles.

The researcher's past involvement with CenteringPregnancy includes participation in writing a grant proposal to the March of Dimes that supported the CenteringPregnancy facilitator training and initial supplies for piloting CenteringPregnancy at the Healthcare Practice. She was also involved in the design and implementation of the evaluation component of the grant and the ongoing self-evaluation of CenteringPregnancy as a quality improvement project within the department of Obstetrics and Gynecology at the Healthcare Practice. She participated in quarterly Centering Facilitator meetings as a member of the CenteringPregnancy Oversight Committee at the Healthcare Practice. These activities ended when the transition to a SMA model of group prenatal care occurred in 2014.

In a previous midwifery position, the researcher initiated the use of the CenteringPregnancy model of group prenatal care within her midwifery practice at a neighborhood health center serving a population of primarily Portuguese-speaking women from Brazil and Cape Verde. She provided prenatal care using this model for three years. The researcher is considered an early adopter of CenteringPregnancy. Her original training as a facilitator occurred in 1990 before

the Centering Healthcare Institute (CHI) was founded or the Centering site approval process had been developed.

Setting

The setting for this phenomenographic research was a large, multi-specialty, multi-office medical practice in the Northeastern United States. Hereafter, the setting will be referred to as the Healthcare Practice for the purpose of protecting study participant confidentiality. Specific office sites will be referred to throughout the study by location pseudonyms chosen by the researcher. The office sites of care were (pseudonyms): Brownsburg, Greenville, Indigo Circle, Orange Grove, White Meadow and Yellowshire. The Healthcare Practice provided CenteringPregnancy group prenatal care from 2008 until 2014. This healthcare was provided in collaborative teams that included obstetricians, certified nurse midwives, nurse practitioners, nurses, and medical assistants.

Within the Healthcare Practice there were 25 office sites. Six of the 25 Healthcare Practice sites offered CenteringPregnancy as an option to women receiving prenatal care. CenteringPregnancy at the Healthcare Practice was initiated in 2008 with start-up grant funding for staff training from the March of Dimes. As of 2013, the Brownsburg and Greenville office sites had completed accreditation through the Centering Healthcare Institute (CHI) site approval process. A part-time project director was in charge of coordinating the Centering start-up, staff training, quarterly staff development workshops, and program evaluation with the assistance of an oversight committee. Due to financial

constraints, the Healthcare Practice decided not to pursue CHI site approval for the other four sites. They also discontinued enrollment of new patients into the CenteringPregnancy program at the end of 2013. The final CenteringPregnancy session occurred in October 2014.

In December 2014 the Healthcare Practice instituted a new approach to group prenatal care based upon the Shared Medical Appointment (SMA) model. As this program was new and not yet evaluated, none of the SMA prenatal care groups were included in this study. This institutional decision by the Healthcare Practice resulted in a modification to the study protocol for recruitment of interview subjects. At the time of the study, there were a total of 57 providers offering group healthcare using models other than CenteringPregnancy to patients with a broad range of episodic and chronic conditions and illnesses at 11 of the offices of the Healthcare Practice. However, due to significant financial and administrative changes occurring at the Healthcare Practice during the time of data collection, the researcher was unable to obtain permission to interview patients who participated in group healthcare experiences based on models other than CenteringPregnancy. Consequently, the original focus of the research study shifted from a focus on privacy in varied group healthcare contexts to focus only on privacy within the context of CenteringPregnancy group healthcare. Although the original intent was to interview participants in various types of group healthcare, only CenteringPregnancy participants were interviewed.

Sample

A purposive sampling plan was employed to select a purposive sample of women within the Healthcare Practice who had chosen to participate in CenteringPregnancy for their prenatal care. In qualitative research, a purposive sample is composed of individuals based on certain characteristics or a set of characteristics shared in common (Robson, 2011; Creswell, 2013). In this research study, participants were purposively selected to enroll in the study if they had attended at least three CenteringPregnancy group prenatal care visits in the prior twenty-four months and were willing to be individually interviewed about their experiences relative to privacy.

Inclusion criteria. As approved by the Institutional Reviews (IRBs) at the Healthcare Practice and Boston College, the inclusion criteria for this study were women of childbearing age who had participated in at least three CenteringPregnancy visits in the prior twenty-four months. As the CenteringPregnancy groups at the Healthcare Practice were conducted in English, all the women eligible for the study were English-speaking.

Exclusion criteria. As approved by the IRBs, there were two criteria for which women were excluded from the study. First, any woman who the researcher deemed she had a clinical relationship with in providing healthcare were removed from the original list of eligible patients. Second, excluded was any woman determined by CenteringPregnancy group facilitators to be a poor

respondent for qualitative interviewing due to pregnancy complications or social situation. An example of this is a woman who had experienced a pregnancy loss.

As approved by the IRBs at the Healthcare Practice and Boston College, the doctoral student researcher chose a purposive sample by utilizing a list of all eligible patients for each of the CenteringPregnancy healthcare groups at the Healthcare Practice. The original list of potential study participants included 272 patient names and addresses. The researcher reviewed the list to identify any patients for whom she had personally provided healthcare in order to exclude them from participation in the study.

Next, an email (Appendix B) from the researcher and the Healthcare Practice Principal Investigator (required by the Healthcare Practice) was sent to the CenteringPregnancy healthcare providers describing the research and requesting their assistance. A study fact sheet was included with the email including a brief description of the study, the process of recruiting study participants and how patient confidentiality would be protected (Appendix C). Additionally, a list of the eligible patients was sent to each CenteringPregnancy group facilitator at the Healthcare Practice via the secure messaging system within the electronic medical record as approved by the respective IRBs (Healthcare Practice, Boston College). CenteringPregnancy healthcare providers were then asked to assist with removing the names of women they deemed ineligible for in-depth qualitative interviewing about privacy within the context of group healthcare due to social or health conditions or other concerns known to the

obstetrical providers. The review of this list was conducted either in person or via telephone, allowing the CenteringPregnancy group facilitators to discuss the study in more detail with the researcher if they desired.

Of the total of 272 potentially eligible participants, there were 17 patients determined to be ineligible through the CenteringPregnancy healthcare provider review of names. In addition, another 21 patients were excluded from the study because their provider was unavailable to provide a review as she was no longer employed at the Healthcare Practice. This resulted in 234 patients who were eligible for participation. The CenteringPregnancy providers received no information about which of their eligible patients actually agreed to participate in the research.

Sample size. Fifteen CenteringPregnancy participants, each from a different group facilitated by seven different healthcare providers at six office sites from the Healthcare Practice, comprised the final purposive sample. The recruitment from multiple sites of care resulted in a sample that was as diverse in age, ethnicity, and other characteristics as possible. As the study progressed, selection of study participants was guided by the characteristics of the previously interviewed patients to help in achieving a purposive sample as diverse as possible. The exact number of interviews required was determined during the analysis of the data.

Sample selection continued until data saturation occurred (Creswell, 2013). The phenomenographic research design incorporated the aim of

discovering a full description and conceptualization of the varied patient understandings of the phenomenon of privacy within the context of CenteringPregnancy. At the beginning of the research, a sample consisting of twelve to 20 individuals was anticipated to achieve saturation (Sandelowski & Barroso, 2003; Marton, 1996).

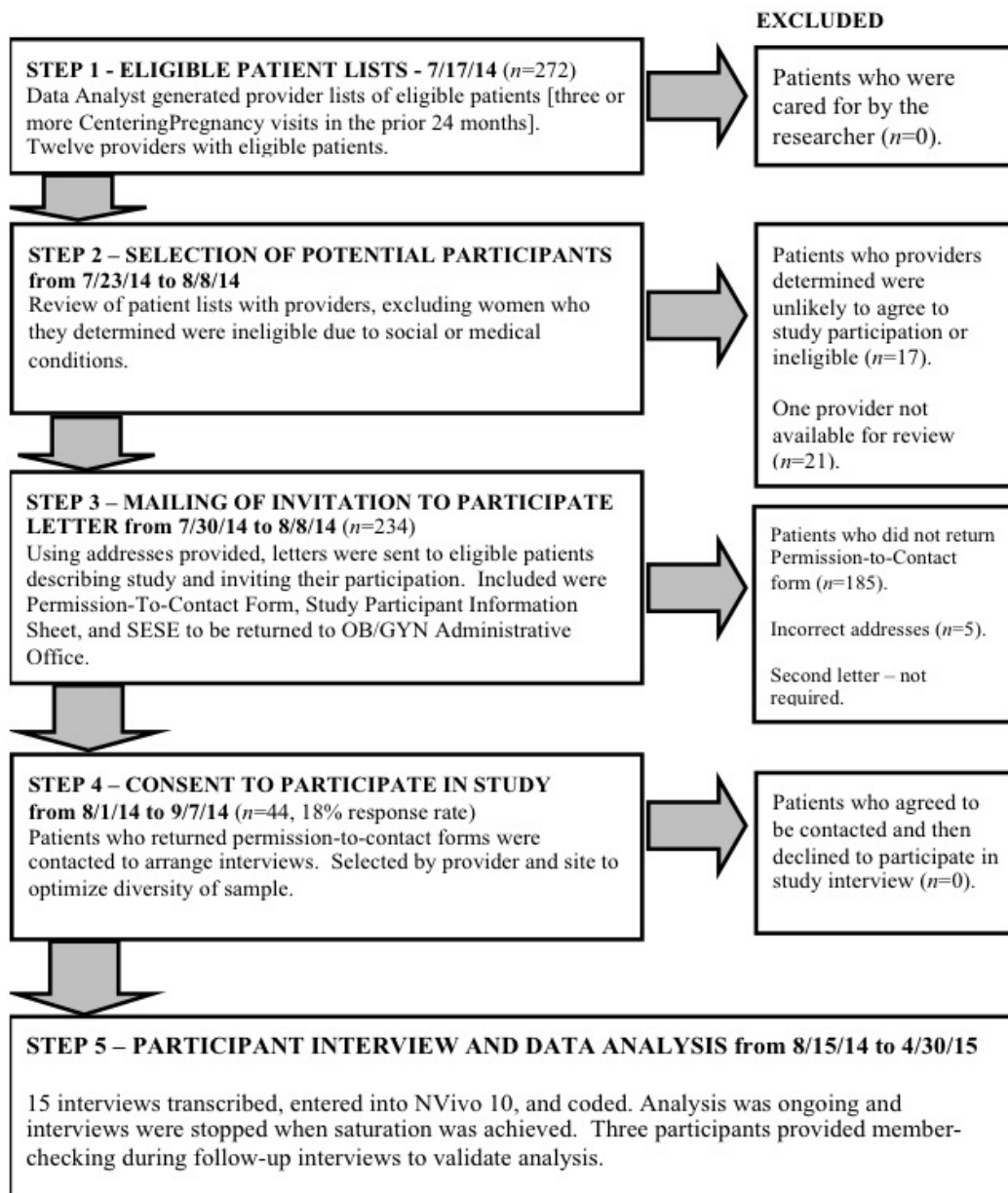
After 10 participants had been purposively selected and interviewed, and their data incorporated into the first round of coding and analysis, data saturation was assessed. After the first 10 interviews, the goal of data saturation guided the ongoing sample selection and determination of the final sample size. The researcher determined that data saturation occurred when no new codes or privacy statements were forthcoming. Data saturation was agreed upon by the doctoral dissertation chair. Thus, data collection ended when a total of 15 separate women had been interviewed and the final sample included these 15 women.

Participant recruitment. According to the protocol approved by the IRB, the 234 patients who were eligible for participation in the study were mailed a letter inviting them to consider participating in the research (Appendix D). This mailing also included the Study Participant Information Sheet (Appendix E), Permission to Contact Form (Appendix F), and a stamped envelope. If a woman was interested in being interviewed, she was asked to complete and return the Permission to Contact form to the researchers at the office where the study materials were stored.

Forty-nine individuals returned permission to contact forms to the researcher. However, as noted earlier, only 15 women were interviewed for this research. The researcher sent a thank-you letter to the remaining 34 women explaining that not all women who agreed to participate were required to be interviewed to meet the aims of the research study. In appreciation for the time and effort of the 15 participants who enrolled and completed an interview, a \$15 gift card was sent to the women after the initial interview.

A flow chart for the study recruitment procedure, including inclusion and exclusion criteria, is outlined in Figure 1.

Figure 1. Sampling Procedure and Time Line



Protection of Human Subjects and Research Integrity

Institutional Review Boards. Approval for the conduct of this study was obtained from both the Institutional Review Board (IRB) of record for the Healthcare Practice and Boston College. The Healthcare Practice required that a

staff member with a doctorate serve as the Institutional Principal Investigator. The person who served in this capacity is a women's health nurse practitioner with a Ph.D. in Nursing. This person facilitated access to institutional support and access to resources during the conduct of this study.

Informed consent. There were several important concerns regarding informed consent for the participation of patients. Consent during phenomenographic research is an ongoing process, not a one-time event (Mazer, 2012). The researcher's clinical background as a certified nurse-midwife and distinct role as a doctoral nursing student researcher were clearly stated in the Study Participant Information Sheet (Appendix E) and reviewed during the consent process at the start of each interview. The researcher had an obligation to respect the wishes of the participants regarding excluding information, for example in responding to a request that the tape recorder be turned off during an interview (Roper & Shapiro, 2000). All participants agreed to have their interview recorded and none of the participants requested that the tape recorder be turned off during a portion of the interview.

The Study Participant Information Sheet included a description of the research, the names of researchers who would have access to the tape recordings of interviews and transcripts of the interviews, and the assurance that confidentiality would be protected through the removal of identifying information and use of pseudonyms of the participants' choice. Also included was a description of the right to withdraw from participation at any time without penalty

and the process for withdrawing from the study. The right to withdrawal information was included in all written and electronic communication with study participants. All women invited to participate in the study were provided with information about how to contact the Healthcare Practice Principal Investigator as well as Dr. Danny Willis (Boston College Associate Professor, Dissertation Chair) with questions, concerns and complaints. This information sheet was included in the recruitment letter mailed to eligible participants.

Confidentiality and data security. Per IRB protocol, all paper documentation for the study was stored in a locked filing cabinet to which the researcher (Laurie Friedman) and the Healthcare Practice Principal Investigator had exclusive access. Paper forms completed at the Healthcare Practice sites other than the study office were transported in a locked courier bag. Telephone communication with participants was conducted on a cell phone dedicated to the study with the phone contract closed at the end of the research project. Interviews were recorded using a Zoom H1 recorder. To protect the interview data, audio files were saved as MP3 files on the secure server of the Healthcare Practice immediately following the interview and then were erased from the recorder. Names and other identifying characteristics were removed from the text transcriptions of the interviews used for data analysis. NVivo10, qualitative data analysis software, was utilized and provided the capacity to audit data access and the data analysis process.

Data Collection

The researcher contacted the participants in the manner they preferred when completing the Permission to Contact form, either by phone or email. Participants chose either to have the interview conducted by telephone or in person. Telephone interviews with the researcher were arranged at a time convenient to the participant and the researcher. In person interviews with the researcher were conducted at a Healthcare Practice office in a private setting and arranged at a time and location convenient to the participant and researcher. The researcher was on site at the Healthcare Practice while conducting telephone interviews and followed the data security protocols described above for both in person and telephone interviews as approved by the respective IRBs. Four women were interviewed in person and 11 women were interviewed by telephone.

Any questions that study participants had about the research were answered prior to the beginning of the interview. The participant was reminded to retain the information sheet detailing the process for contacting the researchers or human subjects' committee. Interview logs, permission to contact forms, study information forms, and participant subject code/pseudonym lists were stored separately from interview transcripts in a locked filing cabinet in the Healthcare Practice office.

Both in-person and telephone interviews were digitally audio-recorded. Interview files were then saved as MP3 files on the secure server of the Healthcare Practice immediately following the interview and erased from the

recorder. Each file was labeled with a subject code and pseudonym chosen by the research participant. A short study information form with demographic and group visit descriptors and the date and location of the interview was completed with the participant to minimize the Personal Health Identifiers (PHI) that were recorded and would therefore require deletion from the audio-recording and interview transcripts. The Interview Protocol Guide (Appendix G) was used to focus the interview questions asked of the participants. As interviews were conducted, some questions were slightly modified, and in some interviews the order of questions was altered to follow the thought process of the study participant. There was a provision in the IRB protocol for the submission of any new questions or new topics of inquiry for approval by the Human Subjects Committee. No new questions were added during the follow-up interview. Interviews took less than an hour. The duration of the interviews was recorded on the Participant Information Form.

The researcher transcribed the interview recordings. This process required listening to the audio recording multiple times. If there were questions about sections of interviews, the interviews were listened to again for clarification or confirmation of meaning or interpretation. Study participants were offered a copy of their interview transcript, which was mailed to them at their request.

Member-checking interviews. Three follow-up member-checking interviews were conducted with three participants. At the time of the initial interview, participants were asked if they would be willing to be contacted for a

brief follow-up interview. The researcher chose five women with diverse characteristics (site of care, provider, parity) to contact for a follow-up interview for member-checking. Three women were available and participated in the member checking process. During the member checking process, participants were asked to determine if their experiences of privacy during group healthcare were depicted in the outcome maps and privacy statements developed as the primary findings of this research. Member-checking provided validation that the findings of the research were reflective of these three women's experiences and conceptualization of privacy within the context of CenteringPregnancy group healthcare.

Data Analysis

This study followed the basics of phenomenographic research incorporating inductive data analysis in an ongoing, iterative manner (de Witt & Ploeg, 2006). Researcher notes were written and entered into NVivo10 after interviews were conducted, with the researcher memoing ideas about areas to investigate further, hunches about concepts, relationships and preliminary analysis as the data analysis process progressed throughout the research. Memoing was documented using the memoing capacity provided in NVivo and used throughout the data analysis process. The researcher also kept a hand-written research diary to document daily notations of the ongoing steps of the research process, questions for review with dissertation committee chair and committee members,

and reminders of study specifics that needed follow up. In this researcher diary, study subject number or pseudonyms were used to protect confidentiality.

While the steps of data analysis appear linear in their presentation, the actual data analysis process was spiral-like, going back and forth between interview notes, transcriptions of interviews, writing of descriptions, memoing, and coding as depicted by qualitative methodologist Creswell in his depiction of the “data analysis spiral” (2013, p. 183).

The written transcripts of the interviews were read by the researcher while listening to the audio files to confirm the accuracy of the transcription process. Each interview transcript was then read again to remove identifying information from the transcript. The transcripts were then entered into NVivo10. Once entered into NVivo, the transcripts were read again and coded using process of initial descriptive coding (Creswell, 2013). NVivo10 software was used to organize the various levels of descriptive coding as well as memos linked to the transcribed interview data. NVivo10 provided the capability for tracking and auditing access to data and the coding process.

After several interviews were coded descriptively, comparison of codes and associated transcripts were read together to generate preliminary sorting of codes into categories or patterns (Creswell, 2013). A summary of the experience of privacy for each study participant was written as the codes were identified for each participant. Based upon the information provided in the interview transcripts, the researcher also wrote a description of the group that each

participant was a part of. Consistent with the phenomenographic research approach, as data analysis progressed and descriptive codes were identified and subsequently grouped together or differentiated based on the similarity and differences in recurring codes, a list of privacy statements was developed for each study participant and compared with the privacy statements of others. This process helped to advance data analysis toward the discovery of phenomenographic findings related to the experience and conceptualization of privacy within the context of CenteringPregnancy group healthcare. An outcome map with supporting privacy statements was constructed through several iterations to succinctly convey the phenomenographic findings. The outcome map, which is central to the presentation of phenomenographic research findings, and the final list of privacy statements and their descriptions constitute the robust conceptualization of privacy developed by the researcher. The fourth chapter of the dissertation (results section) presents the outcome map and the privacy statements reflecting the experience and conceptualization of privacy within the context of group healthcare developed from the interviews with the 15 women who participated in this research.

Qualitative Rigor and Validity

Qualitative research depends on methods employed within the research design to diminish identified validity threats (Whittemore, Chase, & Mandle, 2001, p. 528). A description of how the approaches to sampling, interviewing,

and data analysis aligned with the goals of integrity and rigor of scientific judgments follows.

One potential source of distortion or bias in qualitative research is the researcher. The researcher brought to this study the knowledge and experience of 30 years of nurse-midwifery practice and clinical teaching. This experience has provided the researcher with the desire and interest to listen deeply to the healthcare experiences of pregnant and parenting women. This professional and personal experience is a potential source of bias.

Consistent with approaches in qualitative research that aim to enhance rigor, ongoing memoing and reflexive journaling in a researcher diary provided an approach to making some of the researcher's bias explicit and was a way for others to audit the data generated by the researcher (Roper & Shapira, 2000). Memoing in a reflexive, disciplined and retrievable manner assisted the researcher in clarifying her emerging ideas. Discussion with dissertation committee chair and memoing assisted with limiting the imposition of bias as interviews were conducted and choices made during the analysis of the data. The collaborative supervision of the dissertation chair, committee members, research partners, and member-checking with three of the research participants provided an opportunity to enhance qualitative rigor (Marshall & Rossman, 2011; Munhall, 2012).

The proposed setting for this research was one in which the researcher has not been directly involved in clinical practice. This facilitated a separation of the role of researcher and interviewer from that of healthcare provider. However, the

researcher is employed within the Healthcare Practice where the research was conducted. The researcher benefited from assistance from the Healthcare Practice's Principal Investigator in understanding and negotiating the institution's organization and process. Ongoing consultation with this nurse practitioner and the researcher's dissertation chair was essential in resolving logistical issues as the study progressed.

The purposive sampling procedure as well as the researcher's goal of recruiting a sample as diverse as possible was one aspect of the research design that enhanced the possibility of searching for alternative explanations and negative instances, another aspect of qualitative rigor (Whittemore, Chase, & Mandle, 2001, p. 530).

In addition, the interview methodology employed in this research used open-ended interviews with a provision for member checking as a strategy for enhancing transactional validity.

Transactional validity is defined by Cho and Trent (2006) as:

An interactive process between the researcher, the researched and the collected data that is aimed at achieving a relatively higher level of accuracy and consensus by means of revisiting facts, feelings, experiences and values or beliefs collected and interpreted (p. 321).

To validate the findings, member-checking interviews were conducted with three of the 15 participants. These participants reviewed the study findings with the

researcher and verified that the findings were reflective of their experiences and conceptualization of privacy in CenteringPregnancy group healthcare.

Given the broader context of pregnancy, birth, and mothering within which women's experiences of CenteringPregnancy exists, the researcher's shared gender with the study participants is a factor that seemed to minimize participant hesitancy to share conceptualizations of privacy, intimate thoughts, and feelings. Data analysis focused on descriptive coding and validation of codes through the extraction of in-vivo quotes of the participants' words to provide a description and conceptualization of privacy within the context of group healthcare for the women participating in this research. Thus, multiple components of the study design – purposive sampling, interviewing, and data analysis – interacted together to promote transactional validity.

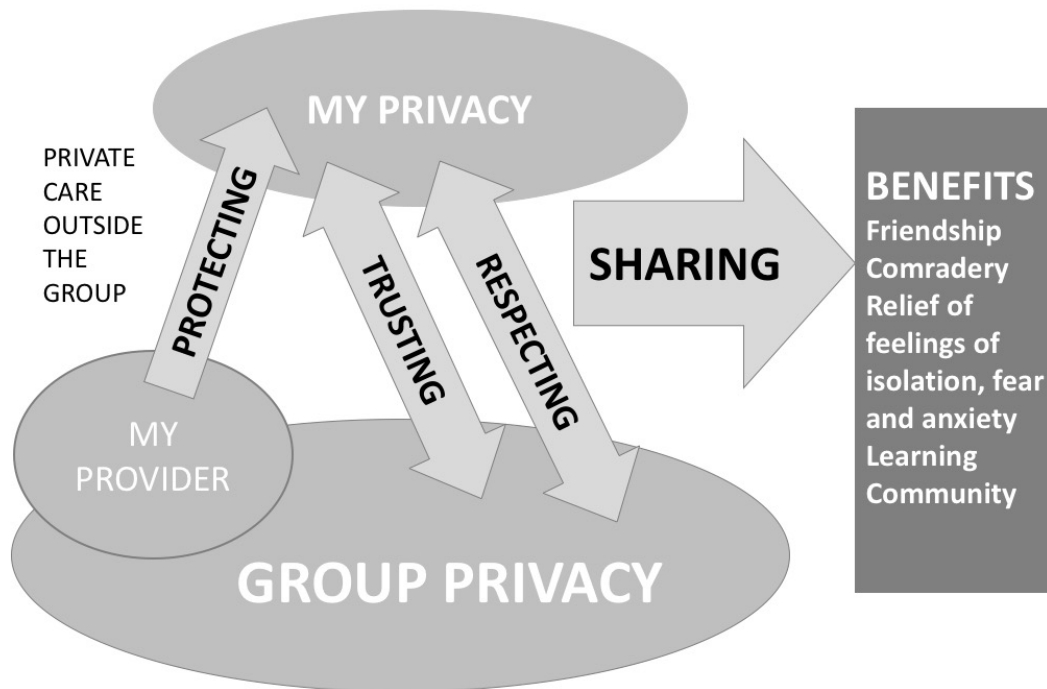
Finally, a report of findings and the implications for clinical practice will be available to study participants and interested staff in a format to be determined through consultation with the Healthcare Practice Principal Investigator and others involved in the research process. Further validation can come from the submission of manuscripts for review by peer-review journals and review by external selection committees for professional or scientific presentation venues.

Chapter Four: Results

The results of this phenomenographic research study, Patient Experience of Privacy While Participating in Group Healthcare, are presented in this chapter. The iterative process of phenomenographic analysis provided the researcher with an in-depth understanding of what the participants considered important about the experience and conceptualizations of privacy in the context of group healthcare as well as how the group healthcare context conveyed benefits to the women.

The presentation of results begins with an outcome map. Outcome maps are used in phenomenography to depict the research findings and display the interrelationships of the major concepts and the corresponding meaning statements inductively derived through the phenomenographic analysis of data (van Rossum & Hamer, 2010). The meaning statements for this research are privacy statements that emerged as the themes in the analysis of interview data. The privacy statements were developed from the interviews with the 15 women who participated in this study. These privacy statements support the outcome map, which summarizes the dynamics of the conceptual results of the research. The privacy statements capture the meanings of privacy closely linked to the interview data. The organizing concepts were developed by the researcher inductively from the privacy statements and were not established a priori.

Figure 2. Dynamics of Privacy in a Setting of Group Healthcare



The outcome map (Figure 2) includes four principal organizing concepts: *My Privacy*, *My Provider*, *Group Privacy*, and the *Benefits of Sharing*. The interrelationships of the four principal organizing concepts are explained by the four relational dynamics of group interactions found to reflect the participants' experiences and conceptualization of privacy: *Protecting*, *Trusting*, *Respecting* and *Sharing*. The relational dynamics are depicted by arrows in the outcome space and describe the experience of privacy that occurs in the relationships among the study participants, their providers, and their CenteringPregnancy groups.

The first relational dynamic of *Protecting* was discovered to be concentrated primarily in the privacy statements referring to the participants'

provider. As such, *Protecting* is discussed within the second organizing concept *My Provider*. The other three relational dynamics, *Trusting*, *Respecting*, and *Sharing* are presented together as a unit rather than in specific combination with other organizing concepts as they connect the other concepts within the overall dynamic of group healthcare.

The demographic characteristics of the study participants are presented first, followed by a presentation of the organizing concepts, relational dynamics, and the corresponding privacy statements.

Demographic Characteristics of the Study Participants

The participants for this research were recruited from a large, multi-specialty, multi-office healthcare practice in the northeastern region of the United States. Seven different providers conducted the CenteringPregnancy groups that the participants attended at six different sites. The characteristics of the 15 women participants (purposive sample) are summarized in Table 4. The town of residence and zip code at the time of the interviews were unique to each woman who was interviewed for the study.

Table 4

Demographic Characteristics of Study Participants

Characteristic	N = 15
Age	Mean - 35 years Range - 30 - 42 years
Education - Years Completed	Mean - 17.5 years Range - 12 - 22 years
Employment/Occupation	
Professional	13
Waitress	1
Graduate Student	1
Race*	
White	13
Asian	1
Asian-White	1
Ethnic Identity*	
Hispanic/Argentinian	1
Irish	2
Indian	1
Jewish/Israeli	1
Latina/Puerto Rican	1
Polish	1
Swedish	1
Vietnamese	1
Not identified	6
Parity	
Primipara	12
Multipara	3
Provider of Prenatal Care	
Midwife (5)	12
Nurse Practitioner (1)	1
Obstetrician (1)	2
Site of Prenatal Care (Pseudonyms)	
Brownsburg	1
Greenville	1
Indigo Circle	7
Orange Grove	1
White Meadow	3
Yellowshire	2

*Race and Ethnicity self described by participants

As noted in Chapter 3 in the section on qualitative rigor, the outcome map and a list of privacy statements organized by concepts were reviewed with three study participants through member checking interviews to validate the research findings. During member checks, participants were asked to determine if their experiences of privacy during group healthcare were depicted in the outcome map and privacy statements. They were then asked to discuss and clarify their responses to the findings. All three participants confirmed that their experiences were adequately represented.

Congruent with the phenomenographic approach, the outcome map is a representation of the broad structure of the experience and conceptualization of privacy in the context of group healthcare (Marton, 1996). The outcome map represents concepts emerging from the data analysis of the fifteen interviews conducted for this study. The text presentation of the results creates a descriptive pathway through the outcome map.

Also consistent with phenomenography, the privacy statements summarized the study participants' experiences of privacy and accompany and support each organizing concept in the outcome map (*My Privacy, My Provider, Group Privacy, Benefits of Sharing*) and the relational dynamics (*Protecting, Trusting, Respecting, Sharing*). Privacy statements are subsumed under each organizing concept and relational dynamic and reflect distinct aspects of the privacy experience. The presentation of findings reflects the whole, or gestalt, of the experience and conceptualization of privacy within the context of group

healthcare as expressed by the 15 women participants and analyzed by the researcher.

Each organizing concept, relational dynamic, and privacy statement is described in this chapter. The voices of the participants are presented with selective quotes from the interviews. These quotes serve as examples of the organizing concepts, relational dynamics, and the corresponding privacy statements. Rich reflections and pointed descriptive quotes extracted from the data by the researcher were chosen to provide a deep description of participant conceptions of the experience of privacy during group healthcare. The names of women interviewed are pseudonyms chosen by each study participant as presented in the quotes that follow. The researcher conducted all of the interviews and is referred to as ‘researcher’ in the interview segments. Interwoven within women’s quotes are nuanced understandings of the interconnections among concepts relevant to the experience of privacy as expressed by the participants.

Modified versions of the comprehensive outcome map highlighting only the organizing concept addressed in any particular section of the results accompany each conceptual section that follows. The accompanying privacy statements address a distinct aspect of the experience of privacy in the context of group healthcare. However, some of the quotes chosen from participants purposefully illustrate a particular privacy statement that incorporates ideas from other privacy statements in order to highlight the interdependence among certain

concepts. To provide an overall orientation for the discussion of the findings, each organizing concept and each relational dynamic is first defined, and then the supporting privacy statements are outlined in a table.

Organizing Concept 1 – My Privacy: Agency of the Self

The first organizing concept is *My Privacy: Agency of the Self*. This organizing concept encompassed the privacy statements that describe the experiences of privacy that are based in each study participant's sense of personhood and her individual body. The privacy statements subsumed under this organizing concept are interpreted to reflect the woman's understanding of her personal autonomy and agency.

My Privacy: Agency of the Self is presented first for several reasons. The concept of 'privacy' is linked to participants' understandings of the self. The Merriam-Webster Dictionary defines privacy as "1 *a*: the quality or state of being apart from company or observation: seclusion; *b*: freedom from unauthorized intrusion, 2 *archaic*: a place of seclusion or 3 *a*: secrecy; *b*: a private matter: secret". If privacy is understood as complete seclusion, then the seeking and receiving of healthcare during any encounter with a provider requires giving up some of one's privacy. In general, for individuals seeking healthcare, making an appointment, agreeing to have the insurance company billed, and signing a general consent for healthcare serves as one's authorization for the intensely personal and private questioning that occurs during history taking, physical examination, and laboratory or other diagnostic testing. For the study

participants, discussing the change of environment in which they received care within the group healthcare setting revealed the ways that privacy is often a taken-for-granted aspect of healthcare.

Second, starting the presentation of findings with the concept *My Privacy: Agency of the Self* is based within the study design. This research design called for the researcher to gather data through interviewing participants who received care in a group healthcare context. Agency, as the power to be in control of one's self, was a core feature expressed by participants as they relayed their ideas about themselves and their experiences of privacy.

The outcome map in Figure 3 highlights the central concept of *My Privacy: Agency of the Self*. It shows the relationship of agency with the other concepts. The privacy statements associated with the organizing concept *My Privacy: Agency of the Self* are listed in Table 5. Major privacy statements are presented in normal typeface and sub-statements related to the privacy statements are italicized below.

Figure 3. My Privacy

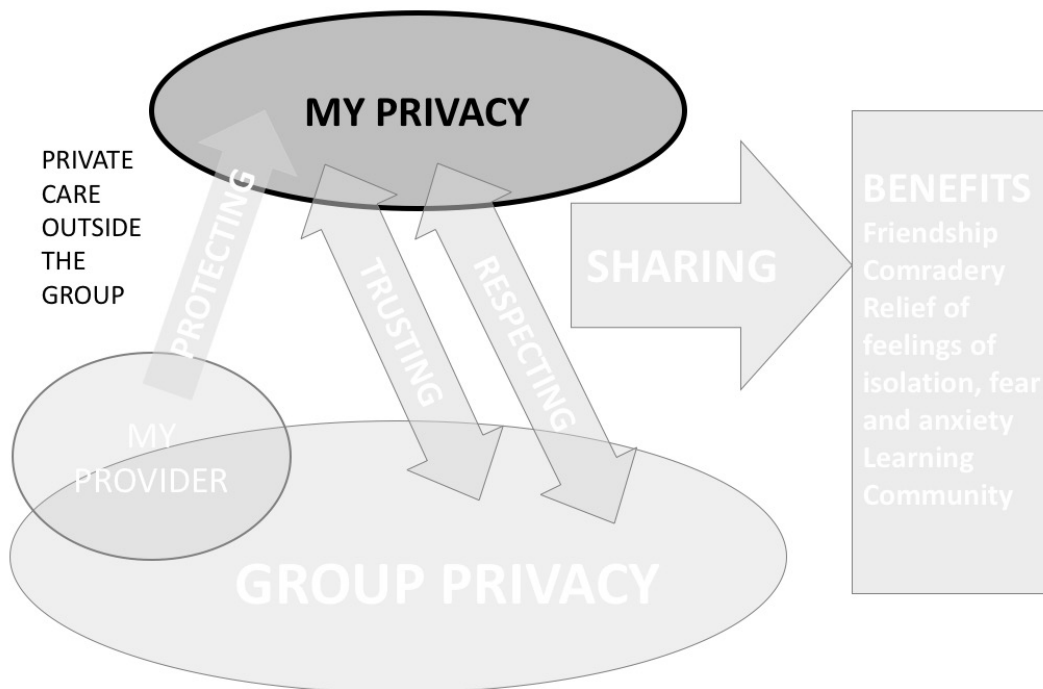


Table 5

Privacy Statements - My Privacy: Agency of The Self

Privacy is voluntary participation in group healthcare.

Privacy is choosing what feelings and experiences I keep private.

Privacy matters less when my pregnancy is healthy.

Privacy is not being seen or heard during the individual check-in and exam.

Privacy is staying dressed for exams, just lifting up my shirt.

Privacy is partial behind a curtain or plant divider.

Privacy is not being overheard when speaking individually with my provider.

Privacy is white noise or music that masks my conversation with my provider.

Privacy is retaining control of my health information.

Privacy is taking my own weight and blood pressure.

Privacy is getting bad news about me first.

Privacy is communicating using an Electronic Health Record.

Privacy is the availability of individual care and communication outside of the group.

Privacy is voluntary participation in group healthcare. All study participants acknowledged that their decision to join group healthcare and their participation specifically in the CenteringPregnancy group was voluntary. Some participants recalled that their providers reminded them that they could return to individual care if for any reason they did not want to continue in the group. Several women thought that a person who chose CenteringPregnancy had to have a particular type of personality and that someone who would be uncomfortable with group care simply would not join a group but would get individual prenatal care. The following quote from Rebecca described her understanding of the voluntary nature of group participation in response to a question asking her to compare her privacy during an individual healthcare visit with privacy during a group healthcare visit. This quote is a general representation of the views of most participants regarding the nature of privacy within group healthcare compared with individual healthcare visits.

I would say, just by the nature of it, an individual visit is definitely more private. But if I would have embarked upon the Centering program looking for privacy then I probably wouldn't have done it. Not because I felt like there was any sort of infringement on my privacy, but definitely because what you are signing up for is a group setting, it's very clear. And it's not for everyone, but for someone who wants to use other people's disclosure and stories as a learning tool, it most definitely is. So there is a certain level of knowing what you're getting into in a group setting. Whereas, in an individual appointment, there is no question at all. The door is closed. It's just you and your clinician and it's 100% private.

Privacy is choosing what feelings and experiences I keep private.

Most study participants expressed feeling like they retained and exercised their agency to decide how, what, and when to disclose personal information to the group. The participants' sense of agency, as expressed in their descriptions of having a choice of whether to share or to keep information or emotions private, was at the core of many women's definition of privacy. In a succinct quote exemplifying the notion of agency regarding the choice to share private information, one participant summarized her definition of privacy as "everything that they know about me is something that I allow."

What information and experiences study participants considered private was varied and individually defined. For example, some participants expressed their preference to keep their weight and pregnancy weight gain private while other participants expressed that they felt comfortable sharing this type of

information with the group. Other women chose not to share complications that occurred during their pregnancies. In some of these situations, women eventually opened up to the group about complications they were facing.

Elizabeth, one of the participants, reflected on her choice never to share her experience with gestational diabetes with the other women in her CenteringPregnancy group. She expressed difficulty pinpointing exactly why she chose not to share but believed it centered on not being comfortable sharing the information with people she did not know well. However, she also stated clearly in another part of the interview that her decision never to share was not based on a lack of group privacy.

I was having a very, very hard time dealing with it [gestational diabetes] on my own. It was ... I was miserable. And for whatever reason I didn't feel comfortable sharing it, I don't know why. It's something that I've thought about a lot, and I can't pinpoint why I decided not to share it, 'cause I shared it with everyone else that I knew. I think maybe, honestly, it was because I didn't know these people that well and we were all in a similar situation, but I didn't want to, I don't know, I just didn't feel comfortable doing it.

In further reflecting upon her CenteringPregnancy experience, Elizabeth expressed disappointment in not making friends within the group. It is noted here that Elizabeth's overall assessment of her experience with CenteringPregnancy was the most negative of any of the women in the study. She explained that her feeling of disappointment was based on her experience in which individual members within her group never shared much personally.

So my group is interesting. It wasn't the biggest group of sharers. I actually had been hoping for a little bit more comradery among the women in the class. And I had been hoping that a few more friendships might form out of it. I think that, for whatever reason, there were a lot of folks that were just a little bit closed. The two women that did share, the two women that I mentioned, the one with twins and the one having the other medical issues, they were kind of the most open out of everyone in the group. Everyone else was just a little caught up in their own stuff that was going on.

The sense of agency expressed by Elizabeth is central to the descriptions of making decisions about sharing within the group healthcare context discussed by many other study participants. That this process results in some participants choosing not to share is evidence that women perceived they retained the power to decide what to keep private.

Other examples of personal experiences that study participants decided to keep private included previous miscarriages and past experiences of depression. For example, within the specific context of a CenteringPregnancy session on the topic of postpartum depression, Rebecca described deciding not to share her personal history of depression within the group, not because she was uncomfortable sharing in her group, but as an example of exercising personal agency.

When we did the session on postpartum depression, I remember we didn't talk about our personal mental health history at all, but I had had depression, like in college. And I thought to myself, in class, I wondered, is that something that

would pop up after my daughter was born. I remember thinking, I'm not going to talk a whole lot about that because that's personal. Not that I felt uncomfortable, but it was just something I chose not to share.

In some ways, the study participants' descriptions of the experience of choosing to keep something private is the complementary outcome of the experience of choosing to share personal information in the group. The study findings reveal that the dynamics of sharing within group healthcare include individual choices women make about what to share, when to share, and with whom to share. Sharing emerged as an important relational dynamic that is discussed later in the presentation of findings under the section heading, *The Dynamic Experience of Group Privacy*.

Privacy matters less when my pregnancy is healthy. Many study participants expressed the opinion that privacy would be more of a concern if something were found to be wrong with their pregnancy. Within the context of a healthy pregnancy and general wellness, privacy receded into the background of women's awareness. Thus, women reflected that they were not often faced with choosing to withhold information. Even when participants recalled something they chose not to share, most women initially expressed that they had nothing they needed to keep private because they had experienced a healthy pregnancy and were leading unremarkable lives. Marie expressed this sentiment. At the same time, she noted that privacy is most important to her in the context of psychological care.

Fortunately, I'm a fairly healthy person. There is not a lot that I would be that concerned about if someone came across. There are certain things that you know you would want to be kept private. Like I said with my pregnancy, I wasn't that worried about [privacy], because it wasn't anything that I was very sensitive about, the information that I was sharing. I think if it was related to psychological care I would feel differently.

Privacy is not being seen or heard during the individual check-in and exam. As the context for describing this privacy statement, the healthcare provider's conduct of physical examinations in the group space was a defining element of group healthcare. Study participants expressed their understandings and conceptions of privacy when they discussed the importance of not being seen or heard by others in the group. Visual privacy for these women included the possibility of some element of the self not being seen at all, for example, remaining dressed during physical assessments (e.g. "belly checks"). However, auditory privacy is different for these women and involves communicating with the provider during the individual exam and what can be heard outside the more private physical exam space. A conversation with the healthcare provider occurring in the private space for physical examinations was perceived to be private to the extent that women experienced the conversation as not being overheard by other group members. Thus, this privacy statement encompasses a wide range of women's desire for visual privacy whenever the healthcare provider physically examined them to assess for fetal wellbeing. It also includes the desire of participants to ensure that there was auditory privacy whenever they shared

information with the provider that they had chosen not to share with the larger group at that moment.

Study participants most often described the physical spaces that were used to conduct individualized prenatal check-ins and health assessments as being ‘private enough’. Four privacy statements constitute the complexity of women’s conceptions of privacy regarding the experience of not being seen or heard during private consultations and/or physical examinations with the healthcare provider. These privacy statements are illuminated by selective quotes from the participants that capture the importance of having a sense of both visual and auditory privacy during the individual check-in and physical examinations occurring during CenteringPregnancy group.

Privacy is staying dressed for physical health examinations, just lifting up my shirt. Most study participants expressed that the physical space for individual prenatal examinations by the providers within the group room provided enough privacy. Participants were asked to describe the environment in which their CenteringPregnancy group occurred. Their responses yielded rich descriptions including thoughtful reflections about their feelings regarding the actual environment where the physical health assessment of the woman’s body (fundal height) and fetal heart tones were conducted. These descriptions were interwoven with expressions of how participants felt about receiving care within the proximal physical space used for the group. Also important for the study participants was the sense of not being seen by other group members during the

actual physical health exams. This is reflected by one of the participants, Izzy, in the following excerpt. Izzy's statements, while short and to the point, exemplify the privacy experience of most of the study participants, revealing how women were comfortable only revealing a little of their physical selves, for example during abdominal exams assessing fetal growth and well being.

Researcher - So that area where you had the physical part of the exam, it felt private enough to you?

Izzy - Yeah, 'cause I only had to raise my shirt and pull my pants down and I never felt uncomfortable.

Researcher - So, it was not as private as an exam room, but kind of private enough.

Izzy - Good enough, exactly. No one would see me.

Privacy is partial behind a curtain or plant divider. Most participants were matter of fact about the exam area that had slightly varying configurations at different sites of care but generally consisted of a massage table shielded by some artificial plants or a standing curtain. Martha, reflecting on her experience of 'private enough', remembered feeling comfortable with the semi-private individual exam space that provided for visual privacy.

They did their best to make it private. We were shielded from the other women by these kind of, I don't remember if they were real plants or artificial. There wasn't a curtain; it certainly wasn't complete privacy. If you wanted to peek on what was going on with somebody else you certainly could have. For me, it was just private enough to give that semblance of privacy.

For some participants, it took time for them to become comfortable being examined in the semi-private space. Several women stated they would have preferred to be examined in a more private area. For example, Anna reported that her group met in a waiting room at the end of the day and when no one else was waiting for an individual appointment. The specific site that Anna described had the most private of the spaces discussed by the women in the study. Anna remembered valuing more privacy for the physical exam when beginning to meet with the provider in her CenteringPregnancy group. As she continued with group healthcare, however, she experienced becoming more comfortable within this semi-private arrangement for physical examinations.

Interestingly, Anna had received prenatal care in Israel during her first pregnancy. She discussed that in Israel fetal growth was assessed with frequent, routine ultrasounds to monitor normal growth and development. Given her previous experience, she expressed surprise at the low-tech nature of measuring fundal height with a tape measure in the United States (US). Anna believed the prenatal healthcare she was receiving in the US was “light” and “bizarre”. However, Anna understood the visual privacy provided for physical assessment as being adequate.

Anna - Yes. Well, that was not the best, to say the least. I don't know how familiar you are with the Ob-Gyn practice at White Meadow [pseudonym], but they have a space at the entrance, which is in front of the front desk. And that is where we had a circle and we met, all of us. They have a little half wall that separates the area where everybody is waiting where those getting IVF or

extra care are sitting. And so, that side, behind the wall, that is where they opened a little bed and that's where they did the measurements. And, I have to say that coming from a different country, that all the care was so light, and bizarre for me. It didn't matter too much, I mean she was measuring with centimeters, so, there didn't seem to be much that I was worried about for my privacy. So it was really ok, but I think if the standard was something more than that, weight, and blood pressure and measuring the belly with centimeters, then she did go to another room.

Privacy is not being overheard when speaking individually with my provider. This privacy statement refers to auditory privacy during the individual assessment and check-in between CenteringPregnancy participants and providers. As described earlier, most of the participants experienced the semi-private exam space as 'private enough'. Anna continued to describe her experience of auditory privacy.

At the beginning I thought that I would have preferred it to be in a separate place. So to have more privacy and to be able to talk maybe if I have things I want to say and be sure nobody else is going to hear. But on the other hand, it enables me to hear what is going on in the room, if I'm missing anything. So, by the end for me it was completely fine that it was like this. Because I saw that I could talk with her and that when people were talking with her I didn't really hear all that was said. And I think we felt good enough with the group, we didn't think that others are trying or interested to hear.

Gaby provided another clear example of this attitude as she described her experience of the individual check-in time.

Gaby - As different women were going to the back to get their check ups, the rest of us were chatting away. So at the most you could hear, you could hear the little Doppler thing, you could hear everybody's heartbeat.

Researcher - So you could hear the babies' heartbeats?

Gaby - You could hear those off in the distance, but the conversations were kept low so you could not hear what they were talking about.

Privacy is white noise or music that masks my conversation with my provider. Some study participants described the use of a white noise machine or music near the physical exam space. It is unclear from the interviews whether this strategy for increasing auditory privacy was used in all the groups and only noticed by some participants or whether some providers (but not others) used this strategy. In the following quote, Elizabeth described the CenteringPregnancy group space, mentioning the quiet music that helped to mask the conversation and interactions with the healthcare provider. As noted above, visual privacy included the possibility of some element of the self not being seen at all, for example remaining dressed during the physical exam. In contrast, auditory privacy was different. Communicating with the provider during the individual exam was felt to be private to the extent that women experienced this conversation as not being overheard by other group members.

It was essentially a conference room at the Greenville Practice (Pseudonym).

Coming in the midwife and the assistant for the group had moved all the tables

to the side. They had set up food and snacks and stuff for us, and the blood pressure cuffs where just on the right hand side, there were two of them. So, as we got ourselves settled, we would go up and check our blood pressures. Then the scale was on the other side of the room, we would check our own weight, record it, and then as we were ready we would go to the opposite side of the room, kind of an area with plants. The midwife had put plants all around the exam table. And I believe she had some quiet music playing kind of by the table so other people wouldn't hear as much.

Privacy is retaining control of my health information. This privacy statement relates specifically to what the women defined as health or medical information within their experiences. The women expressed that they considered themselves to be autonomous selves and they expected to be able to determine what was included in their definition of health information. In general, study participants considered health information to be related to their bodies; this included weight and blood pressure, laboratory test results, medical history, and specific medical diagnoses. How private they wanted to keep these types of health information varied. What did not vary were women's expectations and desires that they were the ones in control of what health information should stay private and who could have access to their health information. The line distinguishing medical or health information and personal sharing was sharply drawn for some of the study participants, but less clear for others. In the following interview excerpt, the researcher asked Lucy to clarify what she considered to be private information within the context of her group healthcare.

Lucy - Well, for me personally, in my own situation where I'm a relatively healthy person, my concern about [my privacy] isn't as high as I would expect others to be. I'm a very professional person as well, and know what should be shared and what shouldn't be, so I guess that I'm sounding confusing and like I'm contradicting myself. I guess what I would consider to be important is that I wouldn't want anyone to have access to any of my record unless they were my medical provider or I felt comfortable sharing. So I wouldn't want my weight, my blood pressure, my blood results, my baby measurements, anything that is directly related to personal information, to be accessed [by] anyone other than my doctor or my nurse. Or actually, in my opinion, anyone at this practice that is directly related to the OB it would be ok to have to it, it didn't need to be by my doctor or my nurse. Meaning I didn't want the average Joe, or some random foot doctor to have access to it, if that makes sense.

Researcher - Ok, so in your mind, the things that you describe, like your weight, and your lab results and your ultrasound results, those kinds of things, are distinct from your personal feelings that you choose to share within a group, or your personal experiences or things like that that you chose to share in a group.

Lucy - Exactly, exactly. I suppose if there were something that I didn't want to share. I wouldn't have to, but other than, you know, true statistics, true medical statistics. For instance, it's not important, I had hoped to have a natural childbirth, it was not important to me to keep that a secret.

As can be interpreted from the excerpt, Lucy had a clear idea that her medical information included all information regarding her body and that only those providers who needed to know this information should have access to it. Other study participants also defined medical information as private and wanted to determine for themselves when to share details with the group. For example, Grace, who did not want her weight to be known by the group, provided an example of keeping one's health information private. In her statements, it is also evident that she perceived her husband, also a group member, as supporting her desire to keep her weight private.

She recalled:

We [participant and her husband] went to meet with the midwife, and my husband would never say the number out loud, because it was his job to keep track of the numbers. And he would always just point. And the midwife looked at my weight, he would never just say the number out loud, in case I didn't want others to hear.

Privacy is taking my own weight and blood pressure. When asked to describe the physical space where their CenteringPregnancy group occurred, many study participants discussed how they felt about getting care in this setting. The range of attitudes expressed by participants about the simple physical measurement of weight and blood pressure illuminates their desire for privacy and threads throughout the experience of prenatal care in a group setting.

While not every study participant was asked to compare their experience of a self-assessment of weight and blood pressure in the group with the usual

collection of vital signs in an individual healthcare visit, some women remarked that the experience of weighing themselves and taking their own blood pressure was more private because they could choose to share the information or not with the group as a whole. As noted previously, Grace described how she had enlisted her husband to help keep her weight private. Several other women recounted that being weighed in a hallway at an individual visit in other healthcare contexts did not feel private enough to them. Gaby described her experience with the physical set up for weight and blood pressure in her CenteringPregnancy group:

When you walk into the right they had a table with literature, things you could pick up, and that is what had the blood pressure monitor on it. They had the scales right there on the side. And then honestly for the weight and blood pressure everyone was getting as much privacy as they wanted, or needed. So usually at the beginning the midwifery assistant was there. I always chose to go check the scale when nobody was there. I would just write it down on the little chart and show the midwife the record, where I recorded it. And I specifically made it a point not to check my blood pressure with anybody around because I have white coat syndrome.

For Gaby, it can be seen that taking her own blood pressure in a private setting was important for two reasons. First, it was important for keeping control of her health information. Second, Gaby believed that privacy (not being seen by others) provided a more accurate blood pressure reading. It was important to Gaby that she not have a falsely high blood pressure reading. She felt that this prevented unneeded and potentially harmful interventions for high blood pressure. For Gaby,

not being seen included both the process of measuring her own weight and blood pressure and the concealment of these measurements. Her explanations further indicated that she felt that the group space provided her the privacy she wanted.

Despite the ways that most study participants found the process of taking their own weight and blood pressure private enough, a few women stated that they would have preferred a more private process for taking vital signs. As illustrated by Rebecca's experience, the potential violation or loss of privacy could be influential for at least some women holding the belief that the group physical examination process and space was not private enough.

Rebecca reflected:

We would step on the scale, which wasn't in any sort of private setting, it was just like in the room next to the table and then anyone could see it if they looked. And we actually kept track of our weight and blood pressure, all of our stats in our own workbook. So it wasn't as if it was really shared with anybody publicly, they didn't make announcements. That was definitely [not private]. You could look at any point in time and see anyone's weight.

Researcher - So it felt like it wasn't as private as you might have liked?

Rebecca - Correct. But that is just me. I mean, I was sensitive about my weight gain during pregnancy, as I think maybe many of the other women were. But we actually never talked about how we felt about that. But that was just my own paranoia.

Privacy is getting bad news about me first. This privacy statement emphasizes the importance and the nuance of agency in the context of women's

experience of receiving healthcare in a group setting and the desire to protect the privacy of health information. As an example, in the following excerpt from an interview with Grace, she revealed that she has considered different aspects of this issue. She demonstrated the general desire expressed by all the study participants to retain control over their own health information.

Grace expressed multiple times her concerns about the possibility of something potentially going wrong during her pregnancy. In such a circumstance, she wanted to be the first person to receive any bad news before anyone else heard. She emphasized the importance of receiving the information first so that she could decide what she felt and how she wanted to handle the information. In the following interview excerpt, she considered the desire to be the first to know about any potentially ‘bad’ information. She also considered how being the first to know would actually occur, given that her husband attended all the CenteringPregnancy groups with her. In her lengthy discussion, Grace pondered the complexity of being pregnant and therefore responsible for caring not only for herself but also caring for her baby. She remained firm about receiving any bad news first despite her considerations of her husband’s stake in the pregnancy. She conceptualized being the first to know as an extremely important way for her to retain control of her health information. The excerpt begins with Grace stating her definition of privacy within the context of group healthcare.

Grace - Privacy means to me the ability to protect any information that you want to protect, and should. For example, if any of those test results have been bad, I wouldn’t have wanted to get that information in a group setting,

because it would have been upsetting for me and it could have been upsetting for the other people in the group, particularly when you are dealing with pregnancy and everyone is in some cases overwrought. They've got enough concerns. Had someone in the group, for example gotten a bad test result, or bad blood work, I'm sure that that information wouldn't have been dumped on them. I'm sure they would have been contacted by phone or in some other way. But the concern was always there, what if this is a bad result and I have to get that information in a public setting. I wouldn't have wanted that. Luckily, we never dealt with that, as far as I know.

Researcher - So you would kind of rely on the providers to be...

Grace - On their discretion.

Researcher - Having discretion that if they thought there was something that was not appropriate to share in the group setting that they would communicate with people outside [the group] in a different way.

Grace - I would say a doubt, a fear, that maybe it had been forgotten. That maybe it wouldn't be necessarily as serious as I thought it would be, but it would cause me concern and that would show up.

Researcher - And with that concern it sounds like your preference to receive that information and have that kind of discussion would be in an individual more private setting.

Grace - Yes, particularly if it's bad information or information that needs to be discussed more in depth, and in private, yes, if I would have my druthers.

Researcher - For you, does that privacy include your husband or not?

Grace - For me?

Researcher - I'm interested in, for you.

Grace - (Pause) If it were something to do with my personal health, and not the health of the baby then that is my business. That's not his. Although by agreeing to the Centering model, I know that it then became information that would be shared with him. So I'm not sure what my answer is. I think that it is my personal information, that I made the decision that it could be shared with him.

Privacy is communicating using an Electronic Health Record. This privacy statement incorporates the examples provided by study participants of choosing to use the secure electronic email communication within their Electronic Health Record (EHR) to increase the privacy of interacting with their provider. The EHR used by the Healthcare Practice provided patients with access to laboratory and other medical testing results and secure email communication that also becomes a part of the person's medical record. Some of the study participants used the EHR to obtain laboratory and other test results and to ask questions confidentially or communicate concerns with their healthcare providers.

A selected quote from Gaby helps to illuminate this privacy statement. Gaby preferred to share her feelings of anxiety privately with the midwife by sending her a question using the EHR. She described her motivation to keep her question private and her preference not to appear dumb to the group as a whole.

I had a question that I thought was dumb, so I wasn't going to ask it in front of everybody. You know what happens when you start Googling medical

information? And I had been eating some cereal bars and then I became aware that they had this ingredient that you shouldn't be eating when you're pregnant, and it said all those horrible things about that causing miscarriages. I emailed the midwife and she did her own research and sent me more reliable things that I could read about it.

Privacy is the availability of individual care and communication outside of the group. This privacy statement reflects the importance of more private communication opportunities outside of the CenteringPregnancy group sessions. Participants willingly accepted the 'private enough' aspects of the group as long as they also had the opportunity to choose more private healthcare as they desired. Several participants stated that the group facilitators made themselves available for individual questions at the end of the group. Women were aware of other group members who used this strategy even if they themselves had not.

As contextual backdrop for understanding this privacy statement, the CenteringPregnancy model of group healthcare allows for interim visits as needed outside of the eight group sessions. At this healthcare practice, the initial visit included a history and physical exam visit with a midwife or nurse practitioner, and an initial visit and another mid-pregnancy consultation with an obstetrician. Some women required interim visits due to pregnancy complications, for example hypertension or gestational diabetes. All women receiving care in a CenteringPregnancy group were aware that an individual visit was available to them if they wished. Study participants described several strategies they employed to create more private communication with their provider. These

strategies included coming early to the group healthcare site or staying late after the group was dismissed to speak individually with the provider.

Sarah was one of the participants who strongly desired access to individual private care. In the following quote, she described her struggles to get pregnant, the anxiety created by her infertility treatments, and how she relied on the emotional support of her physician and midwife.

I had a really long and difficult time getting pregnant with intensive infertility treatments that really stressed me out and made me feel very inadequate and desperate and so it was hard to separate out those difficult feelings with what kind of medical care I was receiving. I really would not have wanted to have to share that with someone other than my husband and provider. The doctor and the midwife I worked with helped me a lot.

Sarah occasionally scheduled individual visits with these providers with whom she had an established relationship in addition to her CenteringPregnancy care. She wanted their support as well as the support from the relationships that developed in her Centering Pregnancy group. Sarah also chose to come to her group early in order to have more individual time with the midwife. She preferred not to share her anxieties about miscarriage, which she described as excessive, out of concern for the other women in her group. As her pregnancy progressed normally without major complications, she reported that her anxiety decreased.

I used to come to the sessions a little early so I could have more time and not feel rushed during the individual time with the midwife. I felt like my anxieties

about my issues with infertility weren't relevant for the other women in the group but I needed to be able to talk about them with the midwife.

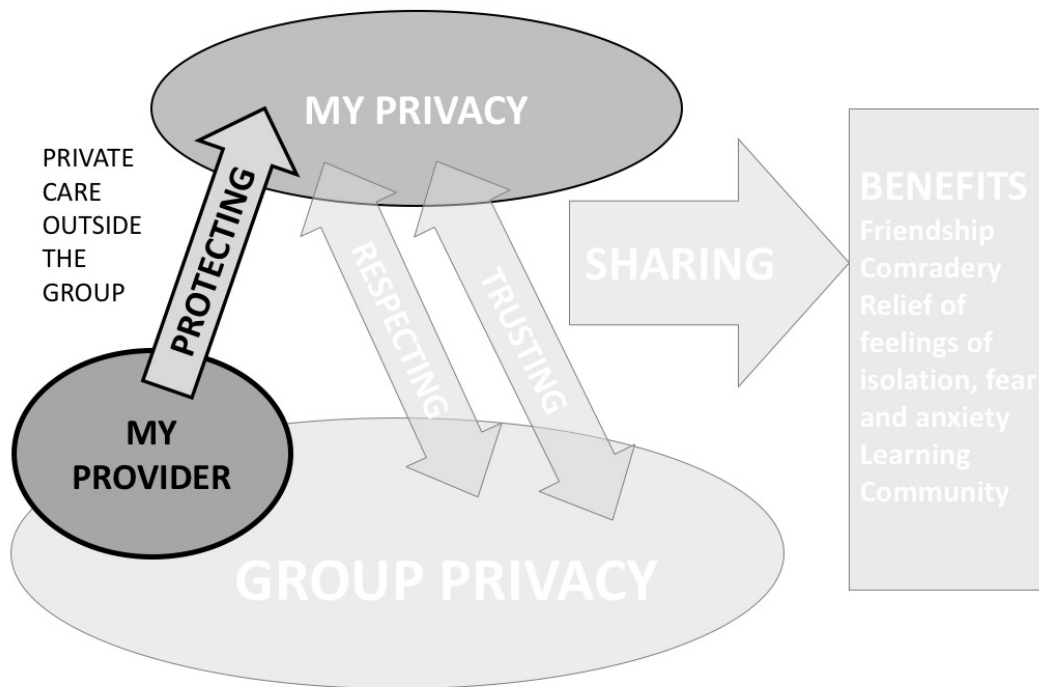
Elizabeth was another study participant who reflected on her appreciation for the individual visits with her obstetrician that were interspersed between CenteringPregnancy sessions as she struggled to cope with her gestational diabetes.

In addition to CenteringPregnancy there were some individual physician visits that I needed to do with my OB. I believe that was just part of the whole package that the practice was offering. I loved my OB. I thought she was great. It was nice to be able to talk to someone individually about stuff that was going on, more personal stuff like the gestational diabetes and all that. At the same time, there wasn't that kind of comradery, obviously of being with eight other women who were all essentially miserable because we were huge and having a hard time getting around. So, just a different experience, and I liked that my care involved both.

Organizing Concept 2 – My Provider: Protecting My Privacy

The second organizing concept, *My Provider: Protecting my Privacy*, is related to the first organizing concept *My Privacy: Agency of the Self* primarily through the relational dynamic of *Protecting*. The Outcome Map in Figure 4 depicts the relationship of *My Provider: Protecting My Privacy* to the other concepts and highlights the specific relational dynamic of protecting. The privacy statements corresponding to *My Provider: Protecting My Privacy* are listed in Table 6.

Figure 4. My Provider: Protecting My Privacy



My Provider: Protecting My Privacy reflects the ways that participants experienced privacy in their relationships with their providers. It includes privacy statements referring to the protective actions of the provider in their role as the group facilitator. The interpreted unifying dynamic of these privacy statements is protecting privacy. Protecting the privacy of the individual group members was found to have several aspects – maintaining a confidential relationship between individual women and their provider, the provider protecting personal information of each group participant, and providers asking permission before sharing a woman’s personal information.

Table 6

Privacy Statements - My Provider: Protecting My Privacy

Privacy is when my provider protects my personal information.

Privacy is my provider asking permission before sharing my personal information.

Privacy is my provider respecting the privacy of others.

Privacy is when my provider protects my personal information. The CenteringPregnancy model calls for two group facilitators. The first is a prenatal care provider, which in this study was a midwife, nurse practitioner, or obstetrician, and the second facilitator was a nurse or a medical assistant. The study participants focused most often on the prenatal care provider as fulfilling the role of facilitator within the group, not the nurse or medical assistant. Women also included experiences in the group and outside the group when they discussed their relationship with the prenatal care provider.

This privacy statement encompasses the experiences of study participants in which they referred to their provider actively protecting their personal information. In addition, this privacy statement reflects the ways in which study participants expressed confidence in the confidentiality of their communication with their provider. All the study participants felt that they had established and continued to have a confidential individual relationship with the provider facilitating their CenteringPregnancy group. In the following excerpt, Anna

expressed her sense of confidence that the midwife facilitating her group would protect the personal information she shared with her.

I think that in this sense it was private enough so that if people didn't want to share they didn't have to. There was this part of each meeting where we were by our own with the midwife. And I felt very comfortable telling her everything and being sure that she would not share it back with the group in any way.

Study participants discussed not only confidence that the healthcare provider would protect information but they also described their experience of having their privacy actually respected or protected by their provider. Participants described examples of privacy being protected when they shared personal information, such as their health history or feelings that they preferred to keep private, only with their providers. When their providers did not disclose this personal information to the group, the reinforcement of confidentiality increased participants' sense of group privacy.

Gaby described a situation where a group member had given birth, but the group member had not given permission to the provider to share any specific information about the birth with the group. She interpreted that the group members refrained themselves from asking probing questions about the group member's birth in order to demonstrate respect for the absent group member's privacy.

For a last appointment one of the women didn't show up so we all made the assumption that oh, she had her baby. And we all started asking questions to the midwife because she probably knew about it. And they basically just told

us that they just couldn't talk about it. They knew we were all in touch by email. And so they told us, if Sheila has not reached out to you guys by email and hasn't told you the details and so until she has let me know that she has already shared this information with you then we cannot talk about. So they were saying that that is how they are going to protect the confidentiality of each of the participants. And that was it. They just told us she is fine and the baby is fine, when she reaches out to you, you guys will find out more.

Privacy is my provider asking my permission before sharing personal information. This privacy statement includes examples of providers protecting personal information by asking permission from individual women before sharing the information with the group. This is another example of the study participants' perceptions of the role of group facilitators. These perceptions emerged as participants described what occurred during the individual check-in time with the healthcare provider.

CenteringPregnancy group facilitators asked women if they were willing to bring their individual questions to the group as a whole. This technique was encouraged during CenteringPregnancy facilitator training. This technique is designed to shorten the time spent addressing questions and concerns with each individual and opens up group discussions by focusing group members on the immediate concerns women bring to a particular group session. Sarah recalled how the midwife facilitating her group asked permission from women individually before bringing these questions to the group as a whole, thereby

protecting each woman's concerns as private until she had given permission for them to be shared with the group.

The midwife would write questions and issues that came up during the individual time, with permission, on a white board. It was good to see what other people were worrying about, and even though it was my second pregnancy I liked the repetition of information.

During group discussions, women often shared stories about friends or family members' experiences with pregnancy, birth and early motherhood. Lucy remembered that the midwife facilitating her group regularly reminded the group to respect the confidentiality of this information. Each time the provider explicitly stated that permission was obtained the study participants' perceptions of group privacy were reinforced.

We would be reminded, if something's getting a little personal to remember that this stuff doesn't leave the room. More importantly, if someone was sharing information about someone else's pregnancy, for example if someone delivered their baby, before that information was shared, it was, "this mother gave me permission and asked me to share with the group that she delivered her baby yesterday." So, it was very clearly stated. It was taken very seriously that we all knew that there was special permission given for any information like that.

Rebecca recalled another example of the group facilitator honoring a group member's confidentiality. Specifically, this was accomplished by the group

facilitator not sharing what she knew about this woman's experience of a pregnancy complication that had resulted in her leaving the group.

It was near the end, but all of a sudden she just stopped coming. And she had told me because we were friends, and clearly the midwife obviously knew about it as well, and so I didn't say anything. That was her news to share if she wanted it. And then after a few sessions, when she wasn't there, somebody said, "Well where is she?" You know? And the midwife said, very tactfully actually, that she had to resign from the group because she had learned about some complications with her pregnancy, and that she was doing ok, but that she was no longer going to be in the group setting, and she was going to be seen individually.

Although Rebecca did not identify the group facilitator's communication here as a violation of privacy, the situation as she relayed it can be understood as in a grey area of managing confidentiality. Some would argue that even stating that this group member had a medical complication of pregnancy is not absolutely protecting this patient's privacy.

Privacy is my provider respecting the privacy of others. The creation of privacy within the relationship between group members and the provider occurred not only with regard to the providers protecting the study participants' private information but it was also generated through participants experiencing the ways in which group facilitators respected the privacy of other group members. In the following quote, Martha reflects on a healthcare provider leaving open the

opportunity for women/group members to share in a manner that Martha perceived of as being respectful. The women's reflections provide evidence that valuing respect for confidentiality within the group context bolstered their confidence that their privacy would actually be respected within the group.

I even remember at one point we were very late, everyone was very far along and it may have been our second to last visit, or last one, somebody asked about how does it feel when the baby drops. And she said this is what it feels like when the baby drops and they said, well, "What is that?" I think that was the question, and she said, "Well, somebody here is carrying really low". And she mentioned that as a way of, if that woman wanted to speak up about her experience.

But she didn't say, "Oh, Beth is carrying really low, why don't you tell everybody what your vagina feels like?" She opened the door a little bit and it was funny because we were all looking around and I don't even remember what the girl's name was, she said, "Oh, you mean me! Yeah!" and she just told everybody what was going on.

It was very respectful the way my midwife brought it up. So that woman was led to feel like if she wanted to mention it she could, or if she wanted to pretend it wasn't her she could.

Organizing Concept 3 – The Relational Dynamics of Group Privacy:

Trusting, Respecting, and Sharing

The third organizing concept addresses the relational dynamics of group privacy and the reflects study participants' understandings of the ways that

privacy in the group developed over time. It emphasizes that women experienced the group existing as a whole, different from merely the sum of the individual members. Within this concept, three relational dynamics are described: trusting, respecting and sharing. In contrast to the dynamic of protecting, which is unidirectional from provider to individual privacy, these dynamics move in two directions, emphasizing that trust, respect and sharing are co-created with the group. Study participants, reflecting upon how privacy was enacted in the relationships within the CenteringPregnancy group, provided the researcher with data to deepen our understanding of these dynamics in the context of group healthcare.

The presentation of findings related to group dynamics advances the phenomenographic results beyond a description of the ‘what’ of privacy experiences to a description of the ‘how’; how privacy is created and maintained within group healthcare. The dynamic of sharing was also identified as the principal action involved in participating in the group. Sharing, however, was discovered to be shaped and influenced by the dynamics of trusting and respecting. The Outcome Map in Figure 5 depicts the *Relational Dynamics of Group Privacy: Trusting, Respecting, Sharing* with the emphasis on how these dynamics connect the other three concepts. The corresponding privacy statements are listed in Table 7.

Figure 5. Group Privacy: Respecting, Trusting, Sharing

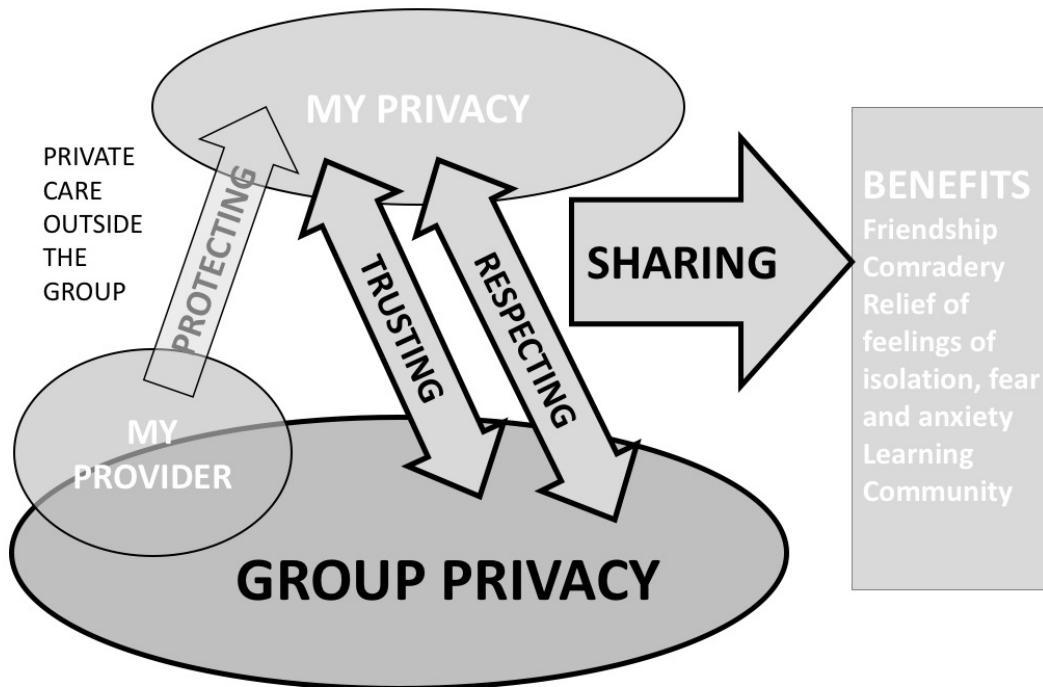


Table 7

Privacy Statements – Relational Dynamics of Group Privacy: Trusting, Respecting, And Sharing

Privacy is trusting that others will keep my personal information confidential.

Privacy is a mutually reinforcing experience of respecting others and feeling respected.

Privacy is not pushing others to share.

Privacy is giving space to others and not eavesdropping.

Privacy is sharing on one's own terms.

Privacy is not feeling pushed or feeling pressured to share.

Privacy is giving permission for my information to be shared.

Privacy is trusting that others will keep my personal information confidential. This privacy statement reflects how trust in group privacy is generated during participation in the CenteringPregnancy group. It includes descriptions of how trust is created in the group healthcare context through the reciprocal or mutual activity of experiencing how confidentiality in the group is actually maintained.

Reflecting on the issue of trusting as a core relational dynamic, Lucy assumed at the outset before she entered her current group that there would be confidentiality within the CenteringPregnancy group. This assumption was based on her past experience with her providers and the Healthcare Practice.

I also trusted the Healthcare Practice. I had been going to them for years for myself and my dad who had had a lot of health issues. So I was excited to be involved in anything that they were running as well. I had no concerns over my privacy or being uncomfortable in that particular scenario.

Another participant, Bea, described her perception of trusting as a dynamic in the group during her experience of taking her weight and blood pressure. In the following excerpt, she connected trust with the feeling that others treated her as an autonomous person. For Bea and other participants, the experience of participating in a group of equally autonomous others created a sense of trusting each other within the group as a whole. For Bea, trusting included a general group ethos, including privacy, but also a feeling of participating in a community while retaining her own sense of agency.

I think it was very much a more welcoming and open atmosphere where we could take ownership. Oh look, we trust you to record your own vital signs. Look at that! And I think that was really nice at building up that feeling of community; and, feeling "I'm in control here."

Rebecca described an activity from one of the final sessions of her CenteringPregnancy group that illustrated the way study participants experienced the intertwining of trusting and sense of community. In the following excerpt, she described her feelings related to trusting and how her trust deepened the meaning of her experience of group CenteringPregnancy.

I remember, near the end when we all were getting close to delivery, we all were delivering within the same window. The midwife had us kind of pull out of the hat these particular little sayings that really were motivational and focused on generating strength and confidence in yourself. And we did an exercise where we all would go through those and we tossed this little ball of yarn to each other, once you would read it, we were standing in a small close circle, and then, at the end, you would look down and there was this really pretty web of the yarn. And she ended up cutting a piece of the yard for each of us to take. I still have it. And I just remember thinking, I am so glad I did this. I would never have had this kind of experience for such a special phase in my life. And it was near the end, but all of the experiences in the classes had built up to that point where you think, "Oh, this is really hokey, I'm going to read some motivational little phrase here." But I think that there was so much depth and meaning behind it because we all understood. And it was the

first pregnancy for all of us. And so that was really special. That was a moment where I thought, “Oh my gosh, there is a lot of trust and friendship here.”

Privacy is a mutually reinforcing experience of respecting others and feeling respected. This privacy statement reflects study participants’ examples of respecting the privacy of others and feeling that others acted to respect their privacy. This peer respect is different from the ways women described the provider respecting members of the group. The following privacy statements specific to CenteringPregnancy illustrate how conceptions of respecting privacy are relationally constituted and grounded in relationship.

Martha alluded to an association between her sense of respecting others by maintain confidentiality within the group, reinforced by the CenteringPregnancy group facilitators, and the general feeling within the group of support for one another.

There was always the reminder [by the facilitator] that this is a supportive, nurturing environment and that everyone was to respect one another. And so I think it wasn’t spelled out over and over again, but we all very much followed that confidentiality, like that vein, it was very supportive of one another.

Privacy is not pushing others to share. This privacy statement exemplifies how important women considered not pushing others to share was to the overall respectful nature of the group. Not pushing others to share was understood by study participants as a way of demonstrating their respect for the privacy of other. Martha described respecting others by taking into account her

own observations and perceptions that some women were more shy than she. In the following excerpt, she discussed how she made an effort to be careful not to push others and not to talk too much during group sessions as a way of respecting others.

Researcher - I remember your saying that you didn't have concerns about your own privacy within the group experience. Did you ever think you had concerns about the privacy of other members of the group?

Martha - Like did I maybe think that other people were concerned about their own privacy?

Researcher - Or did you notice people's hesitancy to share things? Or had people shared things in a smaller group instead of the whole group?

Martha - Yeah, I'm sure that that took place, definitely, in any group situation you can see there are people that are more shy than others. I was very careful also to never push anybody. And also, I tend to be the person that can chat a lot. So I also made sure that I didn't talk too much, so that other people had space to talk if they wanted to.

Another example of not pushing others occurred in cases where a sensitive topic would come up within the group. At these particular times, women held back by not asking probing personal questions. Rebecca offers a clear example in telling a story about a couple who had stopped attending the group after the mid-pregnancy diagnosis of a significant fetal developmental anomaly. In the following passage, she described how the other group members participated in respecting the couples' privacy, specifically by not asking questions.

Rebecca - And nobody asked any questions, I think they all respected, we all just sort of looked at her and were like, "that's too bad, we hope she is ok". And, then after the baby was born, the midwife was able to come back and share the entire story with everybody. Because she had given permission ... But there was nothing else that we were made aware of with anyone else's pregnancies.

Researcher - So it sounds like the expectations about privacy is a mutual thing, where you want your privacy respected and therefore you're going to demonstrate that you're going to respect someone else's privacy too, either by not asking questions, or that it's not just the midwife in the group that is doing it. It's kind of everybody participating in it together. Is that a good description?

Rebecca - Actually it is. I hadn't thought about it until you put it that way, but it is, it definitely is, because we all just didn't ask. I don't know if they didn't ask solely on respecting privacy or also out of like the emotional response, not wanting to infringe upon her. Grief isn't the right word, but her being upset at whatever was going on in her pregnancy. So everyone was sad that she had to leave the group. She was a great member and she did come back to the reunion.

Later, after this mother had given birth, she gave her permission to the group facilitator/midwife to share her story with the group. She, her husband, and daughter were welcomed back into the group when they had their postpartum reunion.

Capturing the centrality of not being pushed to share information, maintaining group confidentiality, and group members respecting each other's privacy, Gaby summarized her concept of privacy in the group in the following quote.

Gaby - I mean also what I said before about being respectful in the group setting about how much you want to share. Part of respecting my privacy is not ever pushing me to say more than I feel like saying.

Researcher - And that you had a sense that the things that were said in the group, that people respected each other's privacy?

Gaby - Yes, definitely.

Researcher - That it was kind of a mutual thing.

Gaby - I'll be honest, in the context of my family, sometimes my husband and I would come back home and to each other, we were like, "Oh my god, I thought I was crazy and had all this paranoia about being pregnant but clearly some other women are worse than me!" So we made those kind of jokes, but that was in the context of my husband and I.

Privacy is giving space to others and not eavesdropping. Participants described purposefully giving space to others by taking turns. For example, this occurred when women explained how they used the weight scales and blood pressure cuffs in a way that did not crowd one another in the self-assessment space. They explained their actions as respecting one another's privacy. Lucy described her experience of group healthcare in which women placed priority on

giving each other adequate personal space during physical self-assessment. She expressed that “staying far away from each other...” was important.

It [self-assessment] was done in a very large conference room, so the group space was done in a circle of chairs, and then on the outside of that there were stations set up specifically for the assessment pieces. One of the stations was blood pressure, and weight. And that was way off to the side, and you kind of did that yourself, along with the nurse, and you wrote down your numbers. So while there was no curtain, we all respected each other’s privacy. We stayed far away from each other while we were doing that piece. Unless you said your numbers out loud. I have to tell you that a lot of us got comfortable. I’d be like “Oh, wow, I gained two pounds this week”, or whatever. So, unless you chose to do that, no one would know because we were writing the numbers down.

Many participants described respecting one another’s privacy by giving others space. This included not looking or listening when another woman was having an individual check up with the healthcare provider. Group members used the strategy of not eavesdropping in order to protect each other’s privacy during the individual assessment and personal check-in time with the provider. Most study participants expressed satisfaction with the semi-private exam space used for individual check-ins stating it provided adequate visual privacy. However, the auditory privacy for masking sound (such as during the Doppler assessment of fetal heart tones) was problematic for some of the participants. Referring to participants’ sense of self and their conceptions of the privacy experience, several

women mentioned their ability to overhear the sound of other women's fetal heart tones in the group space beyond the individual physical exam space.

For some of the participants, hearing the fetal heart tones of another woman was a reassuring and enjoyable experience. For others however, they were more concerned and wondered what would have happened if the provider had been unable to hear the heartbeat because something was wrong. Although this concern was raised by some of the women during interviews for this research, no study participant experienced a fetal demise herself or the diagnosis of a fetal demise during her CenteringPregnancy experience.

Grace described the value she placed on intentionally trying not to pay attention to what other women were saying to the midwife during individual check-in times.

There was no sound protection so anything that you would say to the midwife, should anyone be listening, they could have heard every word. I know that I tried not to pay attention to what was going on in there, but I did feel that it would have been better to have a more private removed space in case there was something you did want to say to the midwife that you didn't want other people to overhear, concerns that you might have, or a past medical history that might be relevant towards your pregnancy that you couldn't discuss with the midwife. So it wasn't necessarily a private space where you were meeting with the midwife. There was the bed that was set up, and there was [a Doppler] to listen to the heartbeat.

Privacy is sharing on one's own terms. This privacy statement encompasses the ways that study participants described the autonomous sharing of personal information. Sharing is a central action that threads through multiple statements of women's experiences of privacy during group healthcare. The sharing on one's own terms statement elucidates women's expressions of agency as they describe the process of disclosing personal information with the group. Sharing on one's own terms includes examples of participants deciding to disclose information they consider private. The choice to share assumes that in some situations women will decide not to share. These situations were discussed in the first section addressing study participants understanding of privacy as choosing not to share within the concept *My Privacy: Self Agency*.

As detailed in the section describing the first organizing concept *My Privacy: Self Agency*, there were times that women chose not to share personal information for a variety of reasons. However, most of the study participants expressed that they felt that over time their group developed a genuine openness about sharing personal experiences. The group openness described by study participants relied upon several facets of privacy, including the core sense that group participants chose to share personal information of their own free will. Grace provided an example of this conception of privacy when she described her experience of freely sharing. Included in her reflection are perceptions of how she viewed other group members within the group healthcare environment.

I know that I didn't hesitate to share within the group. I don't think any of us did. In recalling some of the conversations, I would be surprised to know that

someone was holding something back because there were some pretty open conversations that were happening. I know that I spoke about my fear of labor, and concerns with that, and a desire. For example, I didn't want to watch the videos. I didn't want to watch the childbirth videos. And that became a discussion of what I was worried about in childbirth that I spoke about openly with the rest of the group.

Sharing within the group and perceiving a sense of openness were experiences that study participants linked with trusting in the privacy of the group. While most participants described a general sense of comfort with sharing personal information in their CenteringPregnancy groups, some participants discussed examples of making the choice not to share a particular feeling, questions they had, or an experience. Examples of choosing not to share also highlight participants' experiences that they could share on their own terms. The disclosure of personal information within the group was an autonomous choice for study participants as described throughout the findings thus far.

Study participants referred to their sense that the group was "private enough" enabling them to participate and share within the group. However, privacy was not the only factor women took into account in their decisions to share. Martha described an example of her decision to share in response to a question about hesitating or choosing not to share. Her decision about what to share with the group involved both her own sense of comfort based upon her assessment of group privacy as well as her consideration for the feelings of other women in her group.

I don't remember how it came up but there was some part in the conversation where somebody would mention previous pregnancies, and almost everybody in the group, except for one woman, this was their first, this was to be their first child. But I had had a previous pregnancy. And there was some point in the conversation where that would have been a good place to bring that up if it felt comfortable, and I think I did end up bringing it up. But I hesitated at first, because you don't know how that is going to go. That's a very, very sensitive issue, but of course it was a great place to talk about this because other people had experienced that as well. Definitely, I hesitated bringing something like that up.

The timing of the disclosure of information was discovered to be important to women's experience of privacy and was related to sharing on one's own terms. For example, Bea reflected on waiting to share with her CenteringPregnancy group the information that her first birth had been a Cesarean section. In Bea's description, timing stands out. In particular, she expressed the importance of deliberately taking into consideration the feelings of others, not wanting to introduce undue worry or concern within the group. Therefore, she made a decision to wait to share information about her prior C-section experience with her first pregnancy until a later time in the group development process when the members had gotten to know each other better and were nearing the end of their pregnancies.

The only hesitation I had was in terms of timing. My first birth had been a C-section. And when we started talking, I didn't share any C-section stories at the

initial sessions. Because the timing just didn't seem right. And I didn't want to introduce any concerns for somebody if they didn't have those concerns.

While some of the concerns women initially or later shared within the group context were focused on the physiology of pregnancy and birthing, other concerns women shared centered on relational and intimacy issues. The particular group contexts and composition of group members influenced these discussions. For example, Bea reflected on her observations that some women in her group were more talkative on the subject of stresses in their relationships when their partners were not attending the group.

Bea noted that, at least for some women participating in CenteringPregnancy healthcare, the membership composition of the group influences a woman's experience of sharing in the group. She contrasted her observation of other women's choices not to share "little annoyances they had with their partners when their partners weren't there" with her own willingness to be open about her own conflicts with her husband.

I would share that [feeling annoyed with my husband] even if he was sitting right next to me because that's just the kind of person I am. With some of the other women, especially for the first time through, the first pregnancy, I think they were sometimes more open about difficulties they had, or little annoyances they had with their partners when their partners weren't there vs. when their partners were there. I don't think it materially affected the level of conversation, but I had noticed that there was a little bit of a difference for those particular women.

For the participants in this study, the experience of privacy, including the decision to disclose or not disclose personal information within the context of CenteringPregnancy group healthcare can be understood as a multifaceted process during which women consider and weigh multiple factors. Women's experience of privacy included decision-making about the disclosure of personal information that incorporated their assessments of the privacy within the group. Moreover, it included participants' considering the feelings of others and not wanting to appear foolish or mistaken. Regardless of what factors study participants described as contributing to their decision, their sense of personal autonomy and agency predominated in their descriptions of sharing within the group. That is, they expressed that the decision was theirs to be made based upon their ongoing assessment of individual and group privacy.

Privacy is not feeling pushed or feeling pressured to share. This privacy statement is similar to but different from the former privacy statement labeled *privacy is not pushing others to share*. It reflects the study participants' experience of sharing personal information without feeling required to do so by others in the group. While discussing their experience with sharing personal information, participants emphasized the absence of coercion with language like 'not feeling pressure to share' and 'never feeling pushed' to share. This sense of not feeling pressured to share connotes the freedom to keep private whatever they wanted to keep private. The absence of pressure helped to create an environment that encouraged sharing.

The group facilitators' role in setting the tone within the group was essential. The tone was set that no one should feel pressured to share private or personal information. At the same time, group facilitators' encouraged participation from every group member. In the CenteringPregnancy model, everyone is considered a member of the group: pregnant women, their partners and support people, group facilitators and guest speakers. Every member is invited but not required to participate in group activities and discussion. For example, in her explanation of how she would reassure someone considering joining a CenteringPregnancy group, Lucy stated that "there is absolutely no pressure at all to share anything personal".

You could sit in that group and not say a word. And then you would get out of it what people were willing to share, if that is your comfort level. If you have no desire to share anything about your condition, and the only reason anyone would know you had that condition would be because you joined the group, then there would be no reason. There is no pressure at all.

Anna, another participant described an additional example of a time when the members of her group held back on asking probing questions, contributing to the sharing dynamic in the group and maintenance of the group tone of feeling not pressured to share. Anna was pregnant with her second child while participating in CenteringPregnancy. Her group consisted of nine couples and one woman who attended alone (her partner was unable to attend due to work responsibilities). Anna's husband attended all eight group sessions with her. She explained enjoying her ability to contribute to the group by sharing her previous experiences

and learning about pregnancy and motherhood. However, Anna also felt that others did not ask her questions that might make her uncomfortable. She expressed the importance of retaining her ability to decide what to share within the group.

I was the person to ask, "How was it last time?" Especially since our midwife and her aide [the group facilitators] didn't have kids. I was really the only one. My husband and me were the only ones in the room [with the experience of having gone through a prior pregnancy and childbirth]. So, I think I like this role.

When asked if she were asked questions that were too personal or she was uncomfortable answering, Anna responded, "No". She also stated that as an experienced mom she enjoyed answering questions from expectant women.

I can always decide what I'm sharing and what I'm not, so I didn't feel pushed into a situation where I don't want to say something. I mean you have something to say; maybe it's not everything.

Privacy is giving permission for my information to be shared. This privacy statement reflects the importance of a woman giving permission for her private information to be shared within the group. Study participants reflected their sense of agency when describing their experience of giving permission to providers before their information was shared with the group. The women in this study experienced giving permission as exerting their autonomy and reinforcing the understanding that the listener had obtained the information in confidence.

As part of the standard process of agreeing to receive healthcare in a group, all group members signed a Confidentiality Agreement (Appendix A). When the researcher asked study participants if they recalled signing a confidentiality agreement, all but five of the participants responded affirmatively. Many of the study participants admitted they had not read the confidentiality agreement closely nor did they remember it in detail. However, all study participants were able to recall examples of how the group facilitators had reinforced the concept of group confidentiality with specific reminders and brief group discussions about confidentiality.

Study participants recalled that group facilitators presented group confidentiality in several ways. Many participants remembered a basic agreement with the idea that what happens in the group stays within the group. Grace stated, "What is said here stays here, I think we all respected that...I believe we were reminded in each group."

Other participants described the group honoring the confidentiality agreement helped create an environment that allowed them to feel comfortable asking questions and sharing their experiences without the fear that their personal stories would be shared outside of the group. Lucy explained the procedure used in her group. Her description reflected the process of how women engaged in giving permission to share and clarified that everyone in the group had volunteered to get prenatal care using the CenteringPregnancy model. She also expressed how the confidentiality agreement as a common ground rule within the group fostered

an environment where women could “feel comfortable saying whatever was on our mind.”

Within the very first meeting it was made very clear to us that our personal information would not be shared with each other unless we specifically gave permission. And, then also, that we all as a group should understand that anything that was said in the room truly should stay in the room – that we were all agreeing to be part of this group environment. It was basically said so that we would feel comfortable saying whatever was on our mind. Knowing that the person who was sitting next to me isn’t going to go run off to a colleague of mine and say “guess what Lucy said?”, that was made very clear.

Most of the study participants described the group facilitators’ role as central to the generation of a confidential tone within the group environment. The study participants referenced the establishment of group norms and boundaries, an aspect of group dynamics that can be summarized with the popular phrase “Sharing stays, learning leaves” or the catch phrase “What happens in Vegas, stays in Vegas.” In addition to recalling the group facilitators’ statements about confidentiality within the group, study participants described situations in which the facilitators explicitly asked for permission before sharing any participant’s personal information with the group. Participants recalled multiple examples of group facilitators obtaining consent and modeling the expectation that information or stories about others were not to be shared without first obtaining permission from the person. The group facilitator’s/provider’s modeling and reinforcing of

the group's boundaries succeeded in fostering an environment where women felt safe and comfortable participating in sharing and learning together.

Many study participants described how much they valued hearing about the birth experiences of the women they had gotten to know over the six months of group prenatal care. In most CenteringPregnancy groups, some of the women give birth before the final CenteringPregnancy session. For example, Rebecca described enthusiastically giving the midwife/group facilitator permission to share her birth experience with the group. Furthermore, she expressed appreciation for another couple's willingness to allow the midwife/facilitator to share photographs of their birth with the group.

I can think of two instances where that happened [giving permission]. One was with me. Because after my daughter was born, she [the midwife] happened to come in the next morning. And, I said, "Oh my gosh, tell them everything!" We all wanted to learn about the experience of giving birth and so I said, "Feel free to share every detail." I remember saying that. About three or four days before my daughter was born, the first of the babies in the group was born, actually by a woman who became a good friend of mine, and the midwife delivered her baby. It was a fluke that worked out. And she took pictures and my girlfriend gave full permission for the midwife to share it. So it was really neat for us to get together at that next meeting and see the pictures and know the story. It was nice, because most of us said, "Oh, my gosh, tell them everything", because this stuff was important. So I remember

being so glad that we could see the photos and hear the story directly from the midwife who had just done the delivery.

As noted throughout this presentation of findings related to giving permission for information to be shared, participants' conceptualizations of privacy were described within specific contexts. For example, a few women shared that if a provider, spouse or other person were to disclose their personal information without consent or permission, they would have experienced this as a violation of privacy. However, none of the study participants shared a specific example of this violation actually occurring within the groups they attended. Timing was an important consideration in terms of privacy and the disclosure of information. Some participants described waiting to share feelings and experiences until they felt more comfortable within the group, or the time to share felt right for them. Some women referred to making the choice initially to keep something private. But, then as trust in the group member's respect for privacy developed, and the situation felt appropriate to share personal information, they decided to disclose more private information to the group.

Organizing Concept 4 – The Benefits of Participating in Group Healthcare

The final section of the presentation of results is organized around the concept *The Benefits of Participating in Group Healthcare*. Figure 6 depicts the Benefits as the outcome of sharing within the group.

The privacy statements subsumed under this concept reflect the study participants understanding of what they gained from participating in the CenteringPregnancy model of group healthcare. The central reason study

participants chose to join their CenteringPregnancy group was to navigate through the experience of pregnancy, birth, and becoming a new mother with other women. As demonstrated in the third organizing concept - The Relational Dynamics of Group Privacy: Trusting, Respecting, and Sharing - privacy is an essential element within the group that enables the sharing of personal information. Sharing likewise shapes the development of friendships. Sharing generates comradery and community, helps to overcome feelings of isolation, and supports contextual-based learning. The privacy statements related to the benefits are listed in Table 8.

Figure 6. Benefits of Sharing

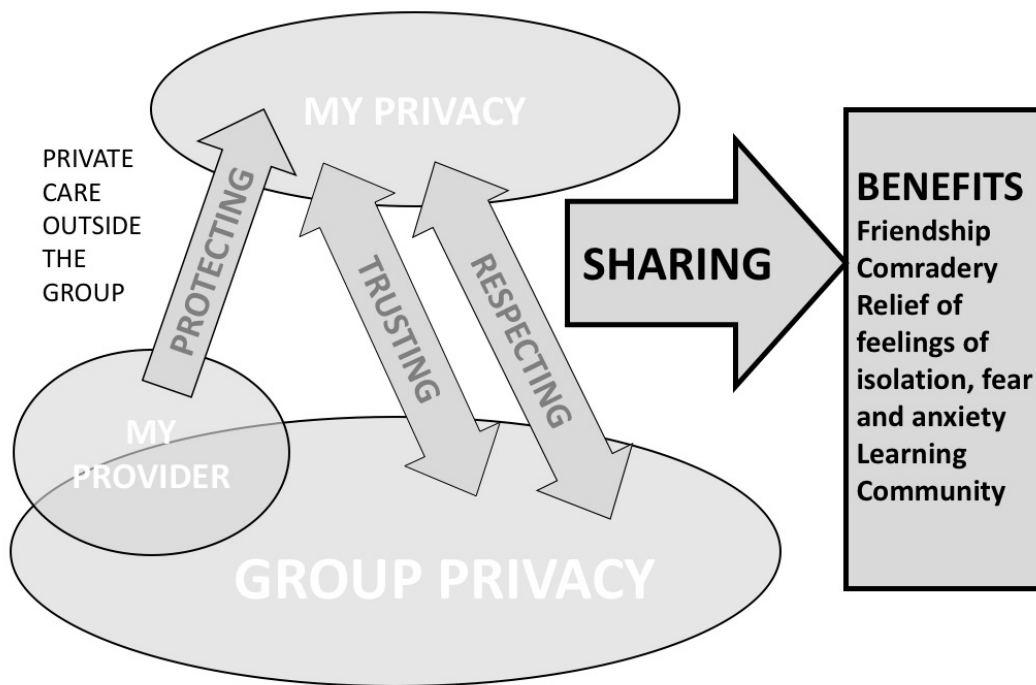


Table 8

Privacy Statements - The Benefits of Participating in Group Healthcare

Privacy in the group promotes friendship and a feeling of intimacy.

Privacy is including intimate partners.

Privacy is excluding men.

Privacy enables comradery in the sharing of the experience of becoming mothers.

Privacy allows sharing that can diminish fear and anxiety.

Privacy supports learning through sharing experiences.

Privacy in the group promotes friendship and a feeling of intimacy.

This privacy statement reflects the ways that privacy is necessary for the creation of a sense of friendship and intimacy to develop in the group. Many study participants stated that they joined their CenteringPregnancy group because they were seeking friendships with other pregnant women. Study participants stated that these experiences of friendship were an important reason they valued their participation in CenteringPregnancy. Without a foundation of privacy, the sharing that enabled these friendships to flourish would not have occurred. Women also claimed that they made friendships that continued after the group. Becoming friends was a benefit of participating in group healthcare, aptly described by Grace in the following passage:

We all got to know each other better from the first meeting until the end. All of us were first time parents. None of us had experiences before. And as the meetings progressed we got to know each other better. We got to know where we all lived, what we did, and just little personal details about each person that brought a familiarity within the group, and a friendship in all of us.

Furthermore, in some of the CenteringPregnancy groups, women offered each other assistance. For example, women would share rides to the Healthcare Practice. Elizabeth highlighted how other members of her group helped each other, specifically in the following excerpt in reference to a woman in the group who was experiencing a difficult pregnancy. This assistance was understood by study participants to be one aspect of friendships that developed among group members.

So one woman was experiencing extreme dizzy spells. And she shared this, in talking about stuff. She had been told not to drive. She would reach out to the group, the poor thing, for rides to the class every week. I believe there was one woman who was living near her and she would give her rides and stuff. So I know that she was also pretty miserable. And, you know, she freely shared that of her own volition.

Highlighting the important benefit of friendship development, a few of the study participants expressed disappointment that they didn't establish more friendships in the group. In at least one group context, Elizabeth attributed the absence of this benefit of friendship to her groups' lack of sharing.

They tried. I would say that they tried. I mean, again, towards the end it was really apparent that people just weren't going to share all that much. Which was too bad, but ultimately, I think that is why I did not disclose the gestational diabetes, because people weren't, there just wasn't that kind of dynamic in the group. But I had hope that more friendships would form out of it.

Martha, who experienced her group as very supportive, offered another perspective on the benefits of friendship – her wish that the friendship relationships could have continued after her group held a reunion. One of the difficulties of continuing relationships after her group was the fact that the geographical locale of group healthcare was convenient while women were working during their pregnancies; however, group members lived in different communities making it harder to get together as new moms.

One thing about Centering that is kind of sad is now it's over, right? And you know, I'm Facebook friends with some of those women but I haven't seen most of them since the reunion, or maybe even before then, since the last appointment. It's so hard to get together. One of the reasons I went into that was that I wanted to make new friends. At the end, I really am not close friends with anybody. I've even changed jobs, and a couple of the other girls have as well, so I don't even work downtown any more. So one of the girls I was close with, she sent me an email and said, "we should get some lunch, now that we've both stopped pumping and can have lunch breaks again". And I said, I don't even work there anymore, but I'd love to have lunch with you. But, I'm probably never going to see you again, we live 45 minutes

apart, and that just really stinks. You know, you build these friendships and then it's all over.

Unlike Elizabeth and Martha, other study participants described establishing friendships within their groups that continued beyond the group reunion. Lucy's group met monthly at a coffee shop for at least six months after their reunion, until many women had returned to work and meeting became more difficult. For Alexandra, living near another woman in her group enabled her to meet at a local playground. She described her groups' continued relationships.

Alexandra - We met every two months, maybe four times. I'm trying to think of all the times. And one woman in particular, she lives somewhat close and we see each other every other week. We'll meet in the playground or I'll see her on Saturday at the library. There is one in particular that I'm very close with because we live closer. But overall, I think we got together every three months.

Researcher - And pretty much everyone in the group has stayed in touch?

Alexandra - Yes, one girl moved back to China, one girl is about to move to New York. So, besides that, yes the entire group is involved. Not everyone can get together every time when we get together, but everyone is in on the emails.

Some participants' descriptions reflected that their sense of privacy is interwoven with the feeling of intimacy within the group. That is, privacy influenced both friendship development and intimacy within the group. Also, women remarked that having a confidential space to share experiences in the

group context created a sense of intimacy not generally found during individual healthcare encounters.

Some aspects of the associations between privacy and intimacy have already been elucidated in study participant descriptions of friendship and comradery within the group. Here, the focus turns to describing the development of intimacy within the group over time. Conceiving of the first session as essentially a group of strangers can capture the group process of developing intimacy. Most participants discussed how the group process facilitated the members becoming “like family” over time. Demonstrating the intimacy developed within the group, the following passage reflects Grace’s sense that sharing physical symptoms and fears was something she usually kept private within her family but that she felt comfortable sharing within the intimacy of her group.

It had a very, almost familial sort of experience, where we could and did talk about almost anything, in terms of physical discomfort, or concerns that we had for our coming labors. I’m sure that was the theme of the last one I was able to attend.

The final two privacy statements describing privacy and intimacy involve the inclusion or exclusion of male partners in the group. These statements reflect the different experiences of study participants based upon the characteristic of the group. Some of the groups the women participated in included partners while some did not. The presence or absence of men had a varied affect on women’s sense of privacy within the group.

Privacy is including intimate partners. The participation of men in the CenteringPregnancy groups ranged from men attending almost all the sessions, to none at all in two groups that included women only. Four of the study participants, Grace, Izzy, Susie and Anna, stated that their CenteringPregnancy groups consisted of couples for almost every session. Following is Anna's description of the diversity within her group.

We were a very international group. Maybe two or three couples were American, and some who weren't completely international, the Americans, many of them were actually mixed. So either the wife or the husband was not from the United States. And we had it in the Whitemeadow (pseudonym) area so we had many people from research background. What we did have, we had one couple with triplets, which were exciting. We had one lesbian couple. We had one woman who came always with herself. Although, a very nice group of people. Talkative, and everyone was participating, so it was very nice.

Two of the CenteringPregnancy groups of study participants included a lesbian couple, with the other couples being a pregnant woman with her male partner. Four other study participants, Alexandra, Gaby, Rebecca and Maria, reported that between one and three men regularly attended their groups, with more partners attending the session focusing on labor and delivery. In the following excerpt, Gaby described her group. Her description reveals her belief that the participation of her husband and the other male partners did not have an effect on the group's sense of privacy.

Researcher - So more women came without their partners than had partners?

Gaby - Yes, yes. And some of them, from my understanding, some of them had to do with schedules not able to get out of work. And some of them, from comments, it had to do more with personal preference. Not theirs, but their husband's preference.

Researcher - Do you think it effected what was said in the group to have men present?

Gaby - Honestly, I don't think so. Both my husband and the other guy that came were very tactful about everything; they knew when to shut up when questions just didn't concern them. I know, just to give you some background knowledge, with a lot of the women we kept seeing each other after Centering ended, with the husbands and everything. And some of us have become friends. So I don't think it really affected things to have the guys there.

Another selective quote from Rebecca provides a description of her assessment of the effect of another group member's husband as a regular group participant. She indicates that he did not deter her from sharing.

Then, of course there was one woman whose husband attended pretty regularly with her, so he was there almost all the time. It's funny, I feel like it's almost as if we got to, we just sort of pretended he wasn't there, poor guy, here he is hearing about all this stuff. It was almost because he was there regularly, even though he did contribute verbally, we sort of accepted him as part of the group and it didn't deter me from sharing anything.

Three other study participants, Lucy, Sarah and Bea, reported that their groups only occasionally had male partners attending their group. As explained in the following quotes, most study participants did not feel that the presence of men in their group had an effect on their experience of privacy. They offered as evidence the types of topics discussed in the group, like physical symptoms of pregnancy that might not normally be discussed by a group of women in front of men. Some participants believed that it was beneficial for the men to hear from other pregnant women in order to understand what their partners were going through.

For example, Grace described the benefits of her husband coming with her to CenteringPregnancy when she was asked to talk about how she felt after attending a group. Grace found it helpful for her husband to gain information about the emotions and physical experiences of pregnancy from other pregnant women. She touched upon her experience of comradery and integrated learning in addition to the education about the experience of pregnancy that her husband obtained by being part of the group. This level of intimacy and sharing normalized what she was experiencing.

I was always happy to go. I looked forward to being about to talk to someone else who was in a very similar situation to mine, meaning that we were kind of along the same points in our pregnancy, and they understood what I was going through. I could get ideas, or I could even just get some sympathy from them because they were experiencing the same thing. I thought it was also good for my husband to be there to hear, you know, someone else might have

been experiencing what I was also going through. You know, any kind of craving or physical discomfort or concern. And it made him more aware of the scope of what I was experiencing, seeing that I wasn't the only one, this was something that everyone experienced and so I wasn't "crazy" for like really needing salt, because everyone really needed salt.

In general, the men were described as listening, learning and participating in a supportive role.

Privacy is excluding men. There were only two study participants' groups that did not include men. Elizabeth's group was exclusively women because of the expressed wishes of one group member. The following quote includes Elizabeth's reaction to her husband, who attended the first group, being excluded from her group. Given her preference for her husband to accompany her to the group, his absence lessened her sense of intimacy while it presumably increased the sense of privacy for the woman who preferred an all-woman group.

Researcher - Did you attend the group appointment alone or with someone?

Did you bring someone to the visits?

Elizabeth - My first appointment my husband came with me. And then, I guess someone in the group said they weren't comfortable having the men involved.

So then, moving forward I just went by myself.

Privacy enables comradery in the sharing of the experience of becoming mothers. Along with friendship, going through the experience of pregnancy together was important based on study participants' assessment of the value of CenteringPregnancy. Going through the same experience (pregnancy,

birth and early motherhood) together made group members feel connected, even to others who were different and unlikely to become friends under other circumstances. Martha expressed her desire for comradery and the sharing of the experience of becoming a mother when answering an interview question about why she chose to participate in CenteringPregnancy.

You know I think I was really looking for a community aspect that was really encouraging to me. I don't have a lot of friends, or colleagues that were going to have children around the same age as my child because I wasn't pregnant at the same time as anyone else. And so I was looking forward to maybe making friends or some sort of comradery around, you know, to share the experience with some people who were going through the same thing at the same time.

Creating a supportive community is a goal of the CenteringPregnancy model and most of the study participants validated that friendship, comradery and a perception of community support were a part of their experience. For example, Izzy expressed her appreciation of how experiencing pregnancy and birth with others normalized the experience of pregnancy.

It was a way of bonding with other first time parents. It was a great experience to just hear that what I was going through was normal. Sometime you say, "Oh my God, what is wrong?" But then you hear that other ones are going through the same thing. So this is not bad anymore. And even when you read about it, or hear about it, when you actually hear from somebody that is pregnant that is going through the same, it makes you feel more

comfortable, more relieved. It's a matter of calm, all the excitement and nervousness that you go through.

I thought it was very unique that it was going to be a group. I remember telling other colleagues and they were like, "That sounds so cool, I wish I had that opportunity when I was pregnant." I think when people hear about it they think its super-cool. I'm glad that I was part of it, and if I would go back in time, I would do it again. So that's my recommendation.

Social support, as evidenced by study participants' descriptions of comradery and friendship, was a valued part of their CenteringPregnancy experiences. They understood that by choosing group healthcare they were relinquishing some of the privacy found in an individual visit in order to meet their needs for support and education during their pregnancy, birth, and early parenthood. Participants described how they grew to trust that privacy would be respected through group members' mutual commitment to confidentiality demonstrated in concrete actions. They described that trust within the group grew over time. This growth in trust among group members, in turn, fostered an environment in which they shared more intimate information and personal stories.

In the context of discussing the ways that CenteringPregnancy was 'private enough' many participants remarked that the increased time spent together, typically two hours rather than a 15-minute individual appointment, supported their sharing on a deeper level. In response to an interview question focused on comparing privacy during group care and privacy during an individual

visit, Anna noted the way a less-private setting paradoxically supported more personal sharing.

Anna - I think that there is a big difference between the privacy in a meeting that is very limited in time, and the Centering follow-up, in the sense that even if you are much more private in an individual visit, you have much less time to get to the point where you are sharing private things. I think that the fact that we were like two hours every few weeks, and we saw our provider for a longer time, that even if, during the ten minutes that we had for the individual visit, it was after a certain amount of time being together and also more prepared to think, that's exactly what I want to say. And if I didn't, then when it came to the end of the two hours I could say to her in the corner, I could say "Oh, I forgot to tell you that."

For me, you can be super private, but if you're not sharing anything, then this privacy doesn't matter. So I think that even if the setting is much less private, you are getting to a place where you say much more private things with your provider.

Researcher - And there is a value in sharing that with your provider?

Anna - I think so, yes.

Researcher - You think it is good to be able to do that?

Anna - Oh yeah, yeah, yeah, it's very important.

Several other participants perceived that more time with the healthcare provider during the group healthcare experience allowed for an enhanced

relationship with her provider. Bea offered the following as an explanation of her experience.

Obviously the individual visit is more private because it's just you and the doctor. I think because the doctor has such limited time to spend with you, I found the individual visit a little more stressful. I felt like I had to come prepared with my list of questions because I knew I would get some number of minutes with the doctor, not a lot of time so I felt like, "I can't be rambling. I need to have my lists of questions. I need to prepare for the individual visits." I found [the group] to be less private but also less stressful because I knew we could take the time to have a conversation, and somebody had already thought about a bunch of the topics I would want to cover and had already laid it out. I thought it was nice that one of the sessions we touched on the topic of birth control, which is not something that would intuitively occur to me. "Oh yeah, I should think about this while I'm pregnant, in case I don't want to get pregnant again in the future." But it's great to have that discussion and to learn about the different options available. I was happy to trade off the privacy for having longer conversations, more well thought out structure and less stress for me.

Privacy allows sharing that can diminish fear and anxiety. Lucy described a situation in which one of the group members delivered her baby early. She described that this information initially made her feel anxious, but then less so after premature birth was discussed in the groups. She also reflected that other women's sharing of other types of information worried her, such as sharing that

their babies were positioned breech. She also expressed that subsequently having the information discussed in the group relieved her anxiety. While fear and anxiety are common problems for women during pregnancy, the study participants described a reduction in these stressful emotions through their participation in CenteringPregnancy group prenatal care.

The person who delivered early kind of scared us a little bit. The midwife, it's not funny, but the midwife basically gave us statistics that one out of whatever many women will delivery early. So she said, "So statistically speaking we won't have any more early births." That made us all feel a little bit more comfortable. And then oddly enough with the breech babies, again

I was hoping for a natural birth so that was a fear of mine. So hearing women say, "I can't believe he or she is breech," over and over again did make me a little more nervous. And then I was really relieved when my baby was not breech. So having that information there was a little more anxiety at that exact time, but then gave me relief. And I suppose that if I also had a breech baby I would have felt like, I'm not the only one.

Privacy supports learning through sharing experiences. The study participants often chose group care in order to learn more about pregnancy, birth and the transition to motherhood. The Centering model includes an outline of topics for each session but stresses the flexibility of this curriculum. Facilitative leadership includes a facilitative teaching and learning style or a partnership learning approach that starts with the questions and problems of the "learners" and then supports a search for solutions through dialogue and accessing shared

knowledge. Using this approach, pregnant women, their partners and the facilitators learn together. The actualization of this goal is well documented in study participants' examples of sharing personal stories and descriptions of their sense of a nurturing learning environment that was created by this sharing.

Study participants valued the learning they gained through hearing the experiences of others more than they did from hearing the expertise of the providers. This included appreciating the shared experience of second time parents, grandparents (who occasionally attended sessions at the end of pregnancy) and providers. As most groups included women with expected dates of birth in a month to six-week range, this sharing included women who were just a little further along in pregnancy or who delivered before others in the group. Sometimes women in the group offered their skills to the group. For instance, offering their skills to the group included a yoga instructor teaching yoga stretches and a pediatrician offering the group information or advice about babies.

Martha provided the following description of her midwife's facilitative teaching approach and associated her sense of being in a supportive learning environment to the feeling of comradery in her group.

The great thing about my midwife as kind of a moderator was that whenever somebody asked a question often times she would say, "Well, has anyone else experienced that, or does anybody else have suggestions for how you've been handling back pain?" So she would really open it up to the group, so we were helping each other. I mean, she is obviously a medical professional and trained and is chock full of wonderful knowledge and a very warm sort of

person, but the last time she was pregnant was probably like 15 years ago.

Here are other women that are pregnant right now and dealing with these issues right now. We had one girl who was a yoga instructor so she was awesome, it was so great to have her because she was like, and you should do this move and try doing this. And she was also breech, and she got her baby to flip around, and all the other breech girls were like, yeah, like her groupies. How did you do it! You know, so that was just wonderful, so nice to just have one another.

Participants often expressed appreciation for the questions of others. They didn't have to think of everything themselves. Other women's questions sometimes came from a different perspective. The study participants described learning from the experience of others as "holistic" or "integrated", or a "flow" of learning more meaningful and useful than information gained by attending classes, reading books or using the Internet. Alexandra compared her experience now with being pregnant for a second time and receiving prenatal care in individual visits with the learning during her first pregnancy with CenteringPregnancy. For Alexandra, individual healthcare lacked both time for learning and the interaction with others that she valued in group healthcare.

Alexandra - I'm pregnant again, and I'm not doing Centering again, but I'll see my OB like twice coming up next week then, well twice with the midwife, once with the OB. There was just a level of learning that I got out of Centering. I didn't have to have all the questions; you know what I mean? It was just a flow of information and it was an hour long and I learned from other people's

experiences and issues and whatever they were going through. You can't really get that one-on-one.

Researcher - Anything else that you think is important for me to know about in terms of your experience?

Alexandra - I mean we shared a lot during our meetings, but we all, as soon as we all started giving birth, we all started emailing each other our experiences. I think that was really cool, I think that was outside of the classes. So I think when we see a group that has continued to be a part of a community together, it says a lot about that group itself. The process and the program and everything. It was a great experience.

Susie described yet another experience in which she associated learning and comradery. As a pediatrician, she particularly valued being with other pregnant women as simply another pregnant woman. She explained that sharing the experience with others helped her focus on being pregnant, and then, "just" a new mom. This was in contrast to focusing on her professional role. In the following quote, she described learning concrete practical advice from the experience of others.

I think that everyone's experiences came in a little differently. One of the couples was having their second child, and they were facing some different challenges with trying to integrate a new baby into their family, but they also had a lot of experience. They had been through the process, they were very familiar with the hospital that most of us were delivering at, having been through that experience, and so that was helpful. And they had good advice

about baby gear and stuff like that. And then a couple of the women were, our group had a wide span in ages, not in ages but in gestational ages of our babies, wider than is typical for most of the Centering groups. Usually there is a month span and ours was like about seven weeks. So there were women about a month ahead in their pregnancies from me, so I had a preview. There were a lot of good opportunities to see what was coming next, which was nice.

As presented above, friendship, comradery, diminished anxiety and fear, and integrated learning are main benefits of group healthcare sharing described by the participants in this study. Not every woman expressed experiencing these outcomes equally. However, for most women, these were the benefits that made group participation worthwhile. These benefits of sharing depend upon the foundation of privacy and respect for the confidentiality of the shared personal experiences within the group healthcare context.

Summary

In conclusion, the four organizing concept are summarized. First, all participants in the research study expressed the desire to maintain control of information they considered private. Although the specific content of what was considered private varied with each woman, it generally included assessments of her physical body, her personal history and emotional experiences. The privacy statements supporting the concept *My Privacy: Agency of the Self* describe women's experience of maintaining their own privacy in a group healthcare setting.

Second, all participants expected and depended on their provider to protect the information they considered private, keeping it confidential within this relationship. Seeking prenatal care, or any other type of healthcare involved many other providers and women expected that the confidentiality of the relationship with her individual provider extended to others involved in her care. What is unique about group healthcare is the special role of the provider in managing and protecting private information within the group. The privacy statements within the organizing concept *My Provider: Protecting My Privacy* detail how women experienced this protection.

Third, the findings within the organizing concept of *The Relational Dynamics of Group Privacy: Trusting, Respecting and Sharing* are the most specific to the experience of privacy in the context of group healthcare, and as such are the most important results of this study. The privacy statements supporting this concept express the ways that privacy cannot be understood solely as a thing, but also as a mutually created dynamic within relationships. These dynamics of trusting, respecting and sharing served to establish and mutually reinforce a sense of group privacy for the women in this study. Each experience of respecting the privacy of others along with the experience of others respecting one's own privacy built a sense of trust among group members over time. This foundation of group privacy was necessary for sharing within the group to occur. And each episode of sharing personal information that was respected again added to the experience of privacy.

The fourth and final organizing concept of *The Benefits of Sharing* encompasses the privacy statements describing the value of participating in group healthcare. Sharing emerged as a central dynamic that relied on a foundation of privacy and lead to the creation of friendships, comradery, decreased fear and anxiety and learning from the experiences of others.

Chapter Five: Discussion

The purpose of the Patient Experience of Privacy While Participating in Group Healthcare research study was to use a phenomenographic approach to investigate privacy as experienced and conceptualized by women who participated in the CenteringPregnancy model of group healthcare. The research questions were:

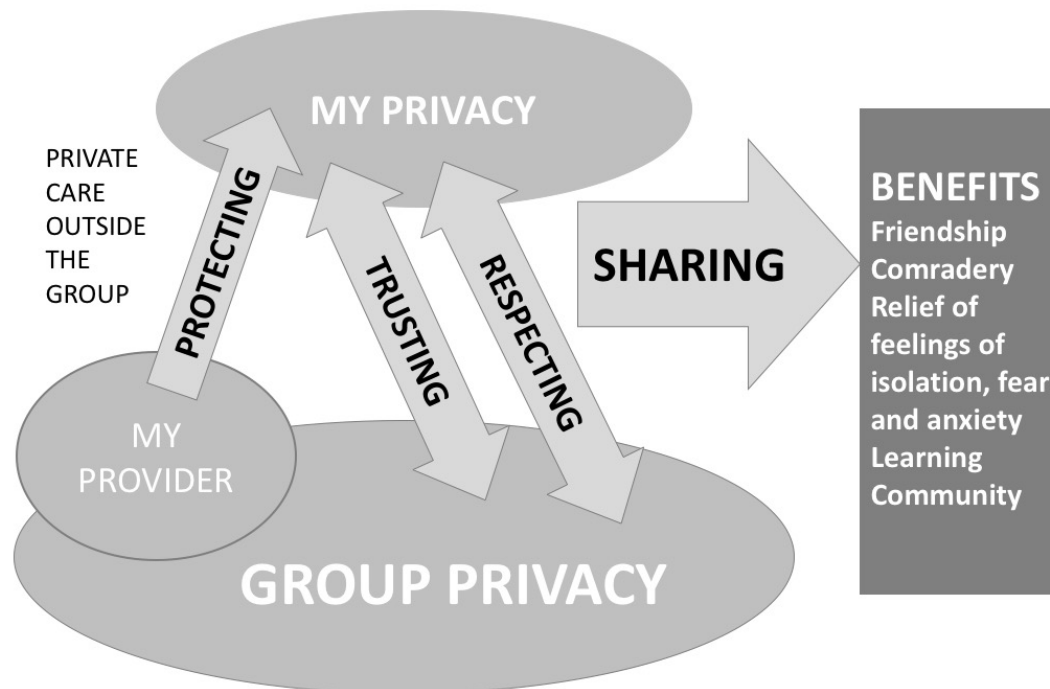
1. What are the privacy experiences of women who participated in the CenteringPregnancy model of group healthcare?
2. How does the patient experience of privacy in a group healthcare care setting differ from the experience of privacy during individual care?

The results of the research were presented in Chapter Four. In Chapter Five, the implications of the four organizing concepts presented in the outcome map will be elucidated. In summary, the implications of the research findings for nursing practice, research, education and policy will be explored.

Major Findings

The first section of Chapter 5 explicates each organizing concept in the outcome map that depicts the Relational Dynamics of Privacy in a Setting of Group Healthcare.

Figure 7. Dynamics of Privacy in a Setting of Group Healthcare



Note. Figure 7 is identical to Figure 2

My Privacy: Agency of The Self. The organizing concept *My Privacy: Agency of The Self* elucidated a central aspect of the study participants' conceptualizations of the experience and meaning of privacy. The specific experiences shared by women regarding their understanding of privacy in this study are particular to the group healthcare context of CenteringPregnancy. However, in both group and individual settings, women expected to choose both what and when to share personal information as well as retain control over who had access to the information they considered private. Agency, as an element of the concept of privacy, is fundamental regardless of healthcare context. This was true for the women in this study during individual visits and their group

experiences. Table 9 displays the major privacy statements included in the concept of *My Privacy: Agency of The Self*.⁴

Table 9

Major Privacy Statements - My Privacy: Agency of The Self

Privacy is voluntary participation in group healthcare

Privacy is choosing what feelings and experiences I keep private.

Privacy is not being seen or heard during the individual check-in and exam.

Privacy is retaining control of my health information.

Privacy is the availability of individual care and communication outside of the group.

The first privacy statement – *Privacy is voluntary participation in-group healthcare* – connected the concept and experience of privacy with voluntary participation in care. Because CenteringPregnancy and other models of group healthcare are different than usual individual care, the principles of confidentiality and protection of privacy that are assumed or implicit within an individual visit need to be explicitly described and explained to patients considering group healthcare.

⁴ See Table 5 on p.106 for a listing of both major and minor privacy statements

The association between voluntary participation and privacy has been described as revealing an ethical component of privacy as it relates to autonomy in the context of healthcare (Grace, 2014) and the importance of the process of informed consent when recruiting patients into group care. The recruitment of patients into group care is a critical aspect for the success of all models of group healthcare (Rising, 2005; Jaber et al., 2005; Noffsinger, 2009; Phillippi & Meyers, 2013). Informed consent during recruitment for group healthcare involves explaining enough about what happens during group care for patients to consider participating. Varied methods for recruitment of patients into group healthcare have been described including informational brochures, posters and marketing videos (GHC, 2001; Rising, 2005; Noffsinger, 2009). Many models rely on provider invitation, leaning on the patient's preexisting relationship with the provider (Noffsinger, 2009). Because privacy is a foundational and facilitative aspect of group healthcare, recruitment materials should clearly address the issue of privacy and confidentiality. In addition, recruitment conversations with staff should address specific patient concerns about privacy. Signing confidentiality agreements prior to joining the group can provide an opportunity for providers to explore, understand and address individual patient's privacy concerns. Additional discussion about a shared commitment to confidentiality should be ongoing in the group, reiterated by group facilitators as appropriate.

The second privacy statement - *Privacy is choosing what feelings and experiences I keep private* - is one of several privacy statements that described

how privacy is related to the process of women choosing to share within the group information and feelings they considered to be private. The findings related to this second privacy statement enhance a large body of knowledge about self-disclosure within the context of individual and group therapy and other individual and group healthcare encounters (Yalom, 2005, Matheson, 2009; Petroni, 2000; Keizer, 2012; Smith, 1997). Women's statements in this study expressed their understanding of the ways in which getting healthcare in both an individual and group setting requires some relinquishing or giving up of absolute privacy. While each study participant had an individualized idea of what she considered important to keep private, every woman emphasized that she wanted to be the one who controlled the determination of what information was shared.

An important issue for healthcare practice with ethical implications is related to the second privacy statement. Women in the study discussed the importance of not feeling coerced to share when they preferred to keep something private. Providers offering group healthcare should strive to create an environment in which women do not feel coerced to share information and feelings. Keeping one's feelings or experiences private could involve only sharing with the provider during the individual check-in time or an individual visit, or choosing not to disclose the personal information at all.

The third statement - *Privacy is not being seen or heard during the individual check-in and exam* – highlighted the importance of physical privacy for one's body during an examination and the protection of confidentiality within the

provider-patient relationship. There was variation among women in the study in terms of how much physical privacy mattered to an individual woman, with some participants expressing more comfort with exposing their body than others. Some participants also noted that as they got to know others in the group they became more comfortable with the semi-private exam space. A component of this increasing comfort was recognizing that everyone was sharing the experience of being examined in the group space.

The physical space for conducting self-assessments and individual exams and check-in was described by women in the study as important for establishing one's sense that group healthcare afforded privacy specifically for prenatal care physical exams and in general. A small number of women discussed that they would have preferred the exam and check-in to take place in a completely private exam room. It is not possible to know how many pregnant women served by the Healthcare Practice declined to participate in CenteringPregnancy due to the semi-private physical exams and check-ins in this study or if women not interviewed for this study chose to leave a group due to discomfort with the physical arrangement of the space.

The physical environment is a critical component for the successful provision of group healthcare that is detailed in the literature on implementation of CenteringPregnancy and other models of group healthcare (Noffsinger, 2009; Rising, 2005). The semi-private space described by the participants in this study allowed most women to feel comfortable during the individual exam. Women

also expressed appreciation for the effort to create a more private space within the larger group room using a corner, curtain or plant dividers to create visual privacy and music or white noise for sound privacy. Creating a feeling of privacy during physical exams does not necessarily require a separate exam room, although some Shared Medical Appointment (SMA) models do utilize private exam rooms for individual physical exams. For example, a healthcare group for patients' managing diabetes might incorporate foot exams, with a patient's permission, but otherwise do not incorporate physical assessment into the care provided in the group setting (Guthrie, 2015).

The fourth statement - *Privacy is retaining control of my health information* - can be applicable in any healthcare setting. Study participants provided rich descriptions of how they negotiated their concern within the context of their CenteringPregnancy group. Exactly which type of health information each participant thought was important to keep private or to share on her own terms varied from woman to woman. The control of personal information, including health information, emerged as a core desire for most study participants. How control over health information was modified by family and social relationships varied across study participants. For example, one woman wanted her husband very involved in the group and her pregnancy and engaged him in keeping her weight gain private. She clearly stated that she believed he had a right to information about the baby because that concerned him. However, she expressed the expectation that she would receive test results, especially anything

that was bad news, in private before her husband or other family members were informed so that she could have time and space to respond and then chose how to share this information with others.

Other women described how their cultural background influenced the information they wanted to share within the group. One participant, whose parents emigrated from India, remarked upon the generational and cultural differences between what she chose to share and what her parents would think appropriate to tell someone outside the family. It is important to note that the sample in this research study was too small to develop a thorough understanding of how culture influences the experience of privacy in group healthcare. However, the findings suggest that providers should incorporate cultural sensitivity to the process of seeking permission to share and the situations when permission is granted to share on an individual basis for each group member.

The fifth privacy statement – *Privacy is the availability of individual care and communication outside the group* – focused on the need for more private modes of care and communication to be available outside of, or in addition to, care in the group. This privacy statement related to the experience of privacy within group healthcare and has implications for the process of group healthcare recruitment and materials. For example, recruitment materials should include a brief mention of the varied options for communication that exists within and outside of the group healthcare setting. In addition, healthcare provider conversations with patients who express concerns about privacy during the group

healthcare recruitment process can offer reassurance that more private modes of communication are provided.

In summarizing the inferences stemming from the privacy statements within the concept *My Privacy: Agency of the Self*, it is important to note that all of the women who participated in the study expressed their desire to maintain control of the information they considered private. There was variation among women regarding what they considered private at a given time and circumstance. However, there were common issues many women considered private, for example, weight gain, past pregnancy losses, a history of mental health problems, and significant medical complications of pregnancy. Likewise, women preferred privacy for physical examinations but grew comfortable with the semi-private exam space in which prenatal assessments occurred. Understanding these aspects of their health history and physical assessment as private did not mean that the women would not choose to share them. Rather, women clearly wanted to be the sole person determining when and with whom these more personal or private aspects of their health histories and experiences were shared.

My Provider: Protecting My Privacy. The second organizing concept – *My Provider: Protecting My Privacy* – elucidated the dynamic of protecting privacy within the healthcare provider-patient relationship as described by the study participants. The meaning of the word ‘protect’ is to “shield from danger, injury, destruction or damage” (Visual Thesaurus, n.d.). Study participants expressed that a violation of privacy would be an injury to their selves.

Furthermore, the women expected that confidentiality within the healthcare system would shield them from damage to their privacy regarding their personal information and their physical bodies.

Women expected their providers to protect their privacy. Women conceptualized and experienced the protecting offered by their providers in several ways as revealed in the privacy statements listed in Table 10⁵. These privacy statements illustrate the importance of the explicit actions of group facilitators that create and support privacy.

Table 10

Major Privacy Statements - My Provider: Protecting My Privacy

Privacy is when my provider protects my personal information.

Privacy is my provider respecting the privacy of others.

These two privacy statements considered together provide descriptive clarity to women's experiences and conceptualization of the role their providers play as facilitators in group healthcare. Study participants described how CenteringPregnancy group facilitators managed private information, supported the agency of each group member, and created and sustained an open, sharing group environment that promoted trust and respect among group members.

⁵ See Table 6 on p. 129 for a listing of both major and minor privacy statements.

Protecting a woman's privacy included the provider's withholding, or not sharing, personal information that the woman herself had chosen not to share within the group. Study participants also discussed relational aspects of trusting and respecting in reference to both group facilitators and other group members. These relational dynamics will be addressed in more detail in the next conceptual section of Chapter Five.

For the women who participated in this study, asking permission from the women to share information was an essential action that demonstrated the provider's commitment to protecting a woman's privacy. An example of this relational dynamic would be a technique recommended during the facilitator training for CenteringPregnancy. This technique involves the facilitators' asking permission to bring all questions raised in individual interactions to the group by saying something like, "that's a great question, I bet others might have the same concern or question. Would you feel comfortable bringing it to the group?" (Rising, 2005).

The group facilitator's asking permission to share information within the group healthcare context reinforces a group norm that personal information is not shared outside the group without permission. Women expressed that being asked by the group facilitators not to share information outside the group contexts themselves and observing other women being asked served to build a sense of privacy and trust of group confidentiality of the group.

The literature on relational dynamics within psycho-educational and therapy groups emphasizes the challenges inherent within the responsibility of the group leader for managing, maintaining and protecting group confidentiality and protecting individual privacy in a group setting (Lasky & Riva, 2006). Yalom (2005) noted the difficulties of balancing the responsibility of maintaining group boundaries with the therapeutic strategy of evoking self-disclosure and encouraging group participation (p. 439). Lasky and Riva (2006) framed their review article regarding confidentiality and privileged communication within group psychotherapy with the difficulties of fulfilling the ethical obligation of group leaders to protect confidentiality in group therapy. From their review of the literature (Lasky and Riva, 2006) and the research of Lasky (2005), who interviewed both experienced and novice group therapists, practical strategies emerged for group leaders to increase group members' understanding of confidentiality. Lasky and Riva stressed the important idea that informed consent for group care is an ongoing process.

Confidentiality is a complex concept for group members and needs to be discussed throughout the life of the group. In order for confidentiality to be maintained and respected by members, leaders need to continually raise the issue, concerns related to it, and how to maintain confidentiality (p. 468).

CenteringPregnancy and other models of group healthcare differ from group psychotherapy in the goal of incorporating medical care into a group setting

rather than an attempt to bring about psychological/interpersonal/behavioral change. However, these groups share the goal of fostering a group ethic that maintains confidentiality. In this research, the women participants in CenteringPregnancy provided multiple examples of the group facilitators' addressing confidentiality throughout the groups. Some of the examples provided details about potentially problematic ways of communicating about other in the group and how facilitators redirected the group discussions into more respectful and appropriate approaches. For example, when someone in the group used a name as she told a story about another woman's experience, the facilitator interrupted to point out that this person may not have given permission to tell her story. The facilitator emphasized that it is better not to use names and to consider how to carefully share the experience of others.

In the group healthcare literature, the role and function of the healthcare providers and group facilitators varies by model. The CenteringPregnancy model, as promoted and accredited by the Centering Healthcare Institute for the purposes of fidelity, has a clear process for training and evaluating group facilitators. This process includes teaching facilitators how to implement a healthcare philosophy grounded in a feminist pedagogy of empowerment (Rising, 1998).

The Centering Healthcare Institute offers basic and advanced facilitator training workshops, a continually updated facilitator's handbook, mother's notebooks oriented toward self-assessment and individual goal setting, ongoing group participant evaluations that provide facilitators with feedback. The fidelity

of model implementation is supported through initial and ongoing site accreditation (CHI, 2015c). Group facilitators are trained to promote participatory learning in a non-hierarchical environment that harnesses the wisdom of the circle (Baldwin & Linnea, 2010; Kennedy et al., 2009).

In a secondary analysis of a large randomized trial of CenteringPregnancy care, Novick et al. (2013) demonstrated an association between more facilitative leadership, as evaluated by trained observers of the groups, and lower odds of preterm birth. This suggests an important connection between the philosophical stance of CenteringPregnancy and improved clinical outcomes. According to Rising et al. (1998; 2004) and Kennedy et al., (2009) this stance incorporated a feminist approach to group facilitation and group processes aimed at empowering group members and harnessing the wisdom of the group as a whole. The Centering Healthcare Institute facilitator training and site approval process is an attempt to assure this approach is implemented in practice (CHI, 2015c; Manant & Dodgeson, 2011).

Most published descriptions of other group healthcare model implementation focus less on explicitly training healthcare providers for the group process than CenteringPregnancy. The Shared Medical Appointments (SMA) promoted by Noffsinger (2009) uses behavioral health providers paired with medical providers as group leaders. The skills for group leadership, including managing the challenges of confidentiality in a group are the responsibility of the behavioral health group leader (Noffsinger, 2009, p. 185).

The *Group Visit Starter Kit* using the Cooperative Health Care Clinic model published by the Group Health Cooperative (2001) briefly discussed group dynamics and facilitator skills. It also offered institutional resources for providers interested in trouble shooting their group healthcare visit. Although there is mention in the literature of the interdisciplinary team learning group management skills from one another (Houck et al., 2003; Lavoie et al., 2013), there was no published research found that included an evaluation of the effectiveness of this approach to the process of group leadership skills acquisition.

The Shared Medical Appointment model was designed to include both homogeneous and heterogeneous groups. For example, homogenous groups may be diabetic or chronic pain patients while heterogeneous groups of patients would be found in the Drop-in Medical Group Appointment (DIGMA) model of group healthcare (Noffsinger, 2009; Stults et al., 2015). The goal of implementing the DIGMA model has often focused upon improving access to care through more efficiently using provider time. Perhaps the mixed outcome results in some group healthcare studies could be better understood if more research included an evaluation of how providers function within the groups and how specific therapeutic elements are included in particular groups.

Turning attention to other group healthcare contexts discussed in the literature, the group-oriented patient self-management scholarship of Lorig (2015) and others (Grey, Schulman-Green, Knafl, & Reynolds, 2015; Schulman-Green et al., 2012) did not explicitly describe the management of confidentiality and

privacy concerns. The patient self-management groups based upon the model developed by Lorig are peer-led groups. In this type of group healthcare, the peer group leaders are trained in both the approach to group management and the educational content of the group. However, issues of confidentiality and violations of privacy are described as arising less frequently in voluntary groups primarily focused on education and support (Lorig, personal communication, 2015).

An exception to the tendency not to address the concepts of confidentiality and privacy within group healthcare literature was found in a qualitative research study of Group Medical Visits (GMVs) by Lavoie et al. (2013). These researchers framed their approach to understanding group medical visits using the work of Kurtz (1997), who studied self-help and support groups and the relationship and roles of professionals to these groups. They distinguished GMVs from self-help groups like Twelve Step Programs and self-management groups that do not include healthcare professionals but rather promote peer leadership within the group.

Lavoie et al. (2013) interviewed 34 healthcare providers and 29 patients who had been engaged in group medical visits using both a Cooperative Healthcare Clinic model and Drop-in Group Medical Appointments (DIGMA) model in rural, northern and First Nation communities in British Columbia, Canada. They identified the social event aspect of GMVs, group affiliation and the co-production of the group medical visit as the key format elements

contributing to GMV success that were common to both providers and patients. Of note was how the social aspect of the group “results in a shift in power, in part because of the presence of peers with shared experiences, but also because providers share the role of adjudicator with patients attending the GMV” (Lavoie et al., 2013, p. 4). Additionally, they found that patients felt safer in a group compared to one-to-one provider patient encounters and positively assessed other group members’ interventions aimed at supporting changes in health behaviors. This contrasted with a negative assessment of provider attempts at promoting behavioral changes during individual care. They also found that the group medical visit shifted the role of the provider from “an expert tasked with defining norms of behavior (the adjudicator role described earlier) and imparting these norms to the patient (as in psychotherapy groups), to that of a facilitator of a group process” (p. 6). They chose the following quote to illustrate how the change in the provider’s role led to an increase in trust for the patient.

I’ve learned to trust him. I trust him more than I used to and that’s important, that bond of trust has to be there. I trust him more when I see that he’s open to learning and figuring out new things that are only happening in group dynamics (Lavoie et al., p. 6).

While Lavoie and colleagues (2013; Wong et al., 2013) have focused their research on the success of group medical visits in delivering patient-centered care, their findings related to the ways group healthcare changed the provider role can be combination with the findings of Novick et al. (2013) to suggested a link

between facilitative process and improvement in clinical outcomes. Similar to these research findings, the results from this study conducted with women participating in CenteringPregnancy suggested that when group facilitators generate a sense of shared responsibility among the group members for confidentiality and privacy, this reciprocal responsibility enables sharing. The findings from this study also suggested that sharing is a core group dynamic leading to the benefits found in participation in group healthcare. Further research into this association of privacy, sharing and benefits of group healthcare could help clarify which components of group healthcare are essential for optimizing benefits to patients and lead to research that specifies the mechanisms of action for the observed improved clinical outcomes for group healthcare.

Relational Dynamics of Group Privacy: Trusting, Respecting, and Sharing. Similar to the second organizing concept *My Provider: Protecting My Privacy*, the third organizing concept (*Trusting, Respecting, and Sharing*) addressed relational dynamics. However, this concept focused specifically upon the relational dynamics among group members and reflected the development of group characteristics and norms over time in contrast to the former organizing concept that focused more specifically on the protective function of the group facilitator in relation to privacy. The major privacy statements summarizing the

concept of *trusting, respecting and sharing* as they relate to privacy in a group are listed in Table 11.⁶

Table 11

**Major Privacy Statements - Relational Dynamics of Group Privacy:
Trusting, Respecting, And Sharing**

Privacy is trusting that others will keep my personal information confidential.

Privacy is a mutually reinforcing experience of respecting others and feeling respected.

Privacy is sharing on one's own terms.

The experiences and conceptualizations of privacy within the group as reflected upon by the women participating in this research are gathered together in these three privacy statements. These three privacy statements emphasize the relational aspect of the dynamics of trusting, respecting, and sharing that developed over time within the context of CenteringPregnancy group healthcare. This conceptualization of privacy as a relational dynamic describes group privacy as co-created by women in the CenteringPregnancy group as they interacted and reflected on their experiences and concerns about pregnancy, parenting, and childbirth. Privacy was experienced and conceptualized by the women in the research study as trusting that other group members in the group would keep any

⁶ See Table 7 on p. 137 for major and minor privacy statements.

personal information shared by a woman in the group confidential. Privacy was also experienced and conceptualized as a mutually reinforcing experience of both respecting other members in the group and feeling respected by members of the group. Furthermore, privacy was experienced and conceptualized as sharing on one's own terms.

Each of the three group dynamics - *Trusting, Respecting and Sharing* - are discussed individually in the next section. The rich descriptions of privacy as a developing dynamic co-created by group members over time are a unique finding of this study.

Trusting. The dynamic of *trusting* described how participants developed a sense of trust that privacy would not be violated within the group. One definition of trust is “reliance; certainty based on past experience” (Visual Thesaurus, n.d.). An additional meaning of trust is “the trait of believing in the honesty and reliability of others”. A third meaning of trust is to “confide commit, intrust or entrust, implying confidence in others”. The findings of this research study focused on privacy within the group healthcare context indicated that trusting in the CenteringPregnancy group encompassed all of the above meanings. The implications are discussed below.

The women in this study initially joined their CenteringPregnancy groups with enough trust in others to overcome their doubts about privacy within the group. Their trust grew as other group members proved their trustworthiness by acting in ways that demonstrated a commitment to maintaining group

confidentiality. Of note is the expressed awareness by study participants of the potential to damage trusting relationships if confidentiality was broken. Women also discussed trusting their providers based upon actions by the providers that demonstrated their commitment to protecting individual privacy. As previously highlighted in published scholarship by Lavoie et al. (2013) and consistent with the findings of this research, trust emerges from the less hierarchical and shared learning environment fostered within the group healthcare context. Trust has been described as an important element in the phenomenon of ‘group cohesion’ as conceptualized within the discipline of psychology (Burlingame, McClendon, & Alonso, 2011). In addition, there is an important body of theory and research about the role of trust in therapeutic clinical relationships and group dynamics (Yalom, 2005; Marmarosh & Van Horn, 2010).

Trust is a cornerstone of the fiduciary relationship between providers and patients and involves the ethic of fidelity or keeping the promises that providers make to patients regarding protecting confidentiality (Grace, 2014). The women in this study reflected upon how, in the context of individual visits, this promise is often tacit rather than explicitly stated. The study participants expressed appreciation for the ways that group facilitators made this promise explicit both in speech and action.

The literature specified that the responsibility for maintaining confidentiality in a group context shifts to some degree away from the provider to the group as a whole, depending on the goals and leadership style of the group.

Lasky and Riva (2006) pointed out that a group leader actually has little control over the actions of other group members. They recommended that facilitators be aware of the potential for the violation of confidentiality and incorporated discussion of this into the process of informed consent for group care. This recommendation has important implications for how healthcare providers and group facilitators orient new members to the process for informed consent in group healthcare. The provision of an orientation to informed consent and confidentiality by group facilitators is supported by the findings of this study with women participants of CenteringPregnancy group healthcare.

Respecting. Demonstration of respect for the patient by the provider is a critical component in the development of the therapeutic alliance (Yalom, 2005; Norcross & Lambert, 2011). Respect is defined as “esteeming or regarding highly” and the “courteous regard for people’s feelings” (Visual Thesaurus, 2015). These definitions correspond with the examples women provided of how privacy was respected in the group healthcare context.

The women who participated in this study described respect for privacy as one element of a more general ethic of respect within their groups that went beyond respect provided by the provider. The mutual display of respect that women discussed as emerging within the CenteringPregnancy group healthcare experience conveys an important element for creating a group tone that supports the sharing of personal feelings, information, and stories. The dynamic of respecting involved feeling respected by others and likewise demonstrating

respect for others. In addition, study participants linked the sense of group privacy with respecting the confidentiality of shared experiences as well as with mutual actions that showed respect for each other's physical privacy.

Related to the women's conceptions of mutual respect and confidentiality of group members' sharing, CenteringPregnancy has mandated that the individual assessment take place within the general group space (CHI, 2015c). Most of the women in this study experienced this semi-private space for individual assessments as 'private enough' despite some initial misgivings. Their evaluation of the semi-private space as 'private enough' paralleled the dynamic of mutual respect for the confidentiality of shared personal feelings, information and stories elucidated by earlier privacy statements. Respecting one another's privacy was described by the women as an enactment of the golden rule of treating each other as you wish to be treated, with each woman wanting and expecting that her privacy would be respected. Therefore, each woman would offer respect for privacy to the other members of the group and expect it in return.

In the literature addressing therapeutic groups, the dynamic of respecting one another was discussed as a contributing factor to the therapeutic alliances that become possible within a group setting (Kivlighan, Miles, & Paquin, 2010). Psychologists referred to the dynamic of trusting when discussing the concept of group cohesion (Yalom, 2005; Burlingame et al., 2011). Group cohesion has been theorized as developing through processes of belonging, trust, and commitment. According to C. C. Wagner and Ingersoll (2013), the development

of group cohesion required “a safe environment that enabled members to feel a sense of belonging, allegiance, mutual liking, trust and commitment to the goals of the group” (p. 16). In their book on *Motivational Interviewing in Groups*, these authors portrayed mature group cohesion as “fostering true intimacy that enables group members to disclose and reveal them and to seek and provide mutual support” (p. 18). Studies of group cohesion used a variety of measures to evaluate this element of group therapy. Despite the lack of consensus on how to measure it, most studies found that an increased sense of group cohesion was associated with improvement in the psychological state of group members, most often measured as decreased anxiety and depression (Burlingame, McLendon, & Alonso, 2011). This positive association of group cohesion with decreases in negative and stressful affect suggests one mechanism explaining the positive outcomes obtained in some group healthcare research.

Researchers who examined violations of confidentiality by group members and group leaders presented the converse of the positive relationship between respect for privacy and group cohesion. This research, while not extensive, indicated that such violations are harmful and disruptive to the therapeutic goals of the group (Yalom, 2005, p. 301). The mixed method exploratory research of Smokowski, Rose and Bacallao (2001) that examined harm resulting from small group experience involved interviews with 87 people who reported having “bad” small group experiences. Of these, 33 interview participants were judged to meet the criteria for “group casualties” due to the

long-term harmful consequences of their bad group experiences. A group casualty in this study was defined as someone who reported experiencing long-term negative consequences resulting from their participation in a small group. Smokowski, Rose, Todar, and Reardon (1999) reported in a quantitative analysis of study data that 15% of the group labeled as casualties ($n=33$) had experienced a breach of confidentiality by a group member, and 9% had experienced such a breach by a group leader, compared with only 2% of the non-casualty respondents reported for confidentiality breach by either a group member or group leader. A breach of confidentiality was the main harmful behavior noted from group members. Smokowski and colleagues concluded with a call for more ethically responsible group leadership that actively addresses the issue of group confidentiality rather than the passive leadership styles reported in their research that allowed violations of confidentiality to occur. The validity of this study was enhanced by the varied types of groups that participants had been a part of, including group therapy, support groups, training groups for therapists, and psycho-educational groups (Smokowski et al., 2001, p. 238). To emphasize their findings, they described a common structure for the groups in which study participants experienced harm.

Most of the groups were highly structured, often in a hierarchical and authoritarian manner. Typically, rigid group norms were set in place forcing active participation and demanding that group members conform

to the group's style of relating regardless of individual capacities
(Smokowski et al., 2001, p. 238).

This type of setting and leadership style was a significantly different one from the trusting and respectful environment described by the women participating in CenteringPregnancy. The research of Smokowski et al. (2001) reinforced the importance of voluntary participation and lack of coercion for fostering a positive group dynamic and a group commitment to confidentiality.

Sharing. The sharing of human experiences and personal stories is reported to be a primary source of many of the therapeutic factors contributing to the benefits of group therapy (Yalom, 2005). Sharing, or self-disclosure, as it is conceptualized in the psychological literature, is a core mechanism of active participation in a group context. The findings of this research linked women's experiences of sharing with the core meaning of privacy discussed in the first organizing concept and the ethical principle of autonomy. The privacy statements addressing the relational dynamic of sharing are listed in Table 12. Given that there was only one major privacy statement relevant to sharing, the researcher included the sub-statements of the privacy statement in order to depict the experience of sharing within the CenteringPregnancy group healthcare context.

Table 12

Privacy Statements – Sharing

Privacy is sharing on one's own terms.

Privacy is not feeling pushed or feeling pressured to share.

Privacy is giving permission for my information to be shared.

As reflected in the privacy statement and its sub-statements, privacy was conceptualized as sharing on one's own terms and included not feeling pushed or pressured to share. Furthermore, the privacy sub-statements highlighted the ongoing and explicit process of permission requesting and permission granting involved in the ethical management of confidentiality and privacy within the group healthcare context. What is perhaps most salient about the descriptions of sharing in the CenteringPregnancy groups offered by the women in this study is their perceived lack of coercion to participate. The dynamic of not feeling pushed nor pressured to share, as well as giving permission for information to be shared, described by the women in this study stands in stark contrast to the descriptions of groups in which participants experience harm (Smokowski et al., 2001; Smokowski et al., 1999).

Related to but different from coercion is the notion of peer pressure within the group context. The literature about peer pressure (Leddick, 2010; Forsyth, 2010) and more specifically about pressures within therapy groups to conform, disclose, and participate is extensive (Kurtz, 1995; Coyne, 2010; Wagner, C. C.,

& Ingersoll, 2013). This characteristic of groups can be harnessed for good or can result in harm (Yalom, 2005). Building on this literature and the findings of this research study, evaluations of group experiences could include an item addressing the experience of feeling pushed in order to monitor any harm and allow the group facilitator to address this component of group culture. The group facilitator could explore participants' perceptions related to the pros and cons of peer pressure to share in group settings and how, if at all, peer pressure relates to participants' conceptualizations of coercion to share.

The Benefits of Participating in Group Healthcare. The fourth organizing concept, *The Benefits of Participating in Group Healthcare*, consisted of the study participants' assessments of what they gained by giving up the greater degree of privacy offered by individual care and sharing with the other women in their CenteringPregnancy group. The privacy statements related to these benefits are listed in Table 13.⁷

⁷ See Table 8 on p. 157, which includes sub-statements.

Table 13

Major Privacy Statements – The Benefits of Participating in Group Healthcare

Privacy in the group promotes friendship and a feeling of intimacy.

Privacy enables comradery in the sharing of the experience of becoming mothers.

Privacy allows sharing that can diminish fear and anxiety.

Privacy supports learning through sharing experiences.

The benefits experienced by the women in this study validated the CenteringPregnancy model's stated general goals of support and education (CHI, 2015b). Privacy as experienced and conceptualized by the women in this study was found to promote friendships and feelings of intimacy. Privacy enabled comradery in the sharing of experiences (namely, being pregnant and becoming a mother). Furthermore, the privacy statements reflected that privacy allowed for the sharing of experiences, which diminished women's fears and anxieties. Lastly, privacy supported women's learning through the sharing of experiences.

Yalom's therapeutic factors in group therapy. The benefits of group participation as reflected in the privacy statements and described by the women in this study can be linked with many of the therapeutic factors of group therapy categorized by group therapist and theorist Irvin Yalom (2005). Yalom's therapeutic factors drew upon client/patient and therapist experiences as well as

research evidence. He acknowledged that the therapeutic factors are neither exhaustive, exclusive, or easily operationalized categories for the purposes of measurement (p. 2). Although there are classifications and groupings of therapeutic factors other than those discussed by Yalom, as well as ongoing attempts to measure and link therapeutic factors to outcomes (Kivlighan et al., 2010), the following discussion relied upon the therapeutic factors of group therapy described by Yalom. The therapeutic factors are briefly summarized and then discussed in relation to the study findings.

Instillation of hope. Many settings for group work bring together people struggling with a common problem made more difficult by depression and despair (Silverman, 2010). Yalom (2005) suggested that the instillation of hope is related to the power of expectation, which enables the group's work to harness the belief in the efficacy of group therapy and enhance the self-efficacy of individual members (p. 4). He also credited groups with a unique ability to instill hope through offering the experience of others successfully coping with adversity, either in the past or present (p. 6).

Yalom's (2005) therapeutic factor addressing the instillation of hope incorporated a focus on expectations or belief in the efficacy of group therapy. Other scholars have written about expectations. For example, expectations have been found to play a significant role for women and their partners as they experience birth (Kitzinger, 2011; Simkin, 2013). The CenteringPregnancy groups that the women described in this study enabled the women to share their

hopes along with their fears during pregnancy and to share their birth experiences during the final reunion session. This is similar to Yalom's conception of the instillation of hope.

Universality. According to Yalom (2005), "After hearing other members disclose concerns similar to their own, clients report feeling more in touch with the world and describe the process as a 'welcome to the human race' experience" (p. 6). Within the dynamics of group encounters, the unique stories of individual members are shared. Common threads of human experiences of suffering, loss, coping and change can generate a sense of belonging in group members as they see their own experiences in relation to others' experiences and reflect on the greater universal human experience. With regard to the benefits of group healthcare discovered in this research study, the comfort and support of sharing the experience of pregnancy, birth and becoming parents were clearly expressed by the women interviewed. The content of these expressions can be seen as reflecting universality as described by Yalom.

Imparting information. A classroom setting is perhaps the archetypical group in which the teacher or leader in the classroom has the goal of imparting information. Yalom included two aspects of sharing information, the didactic instruction of the group leader and the direct advice from group members. The participants in this research study offered examples of both. The imparting of information by the group facilitator as well as by the members of the group was central to the functioning of the CenteringPregnancy groups described by the

women in this research. They also expressed that they valued the contextualized learning from others even more than the didactic information offered by the providers.

Altruism. As groups develop they can provide opportunities for members to help each other both in concrete ways and by listening to one another and sharing emotional support. Yalom's (2005) therapeutic factor of altruism recognized that there are mutual benefits to helping others that accrue to the helper and those who are helped.⁸ While not specifically conceptualized as a finding of this research study, altruism can be understood as relevant to the women's experiences and conceptions of privacy. The mutuality of altruism mirrored the mutuality of respecting privacy that developed within the groups described by the participants in this study.

The corrective recapitulation of the primary family group. Yalom (2005) stated that "the therapy group resembles a family in many aspects: there are

⁸ Yalom began his discussion of Altruism with the following old Hasidic story first used by his co-leader Paula West (pseudonym) to open a group for advanced cancer patients. A rabbi had a conversation with the Lord about Heaven and Hell. "I will show you Hell," said the Lord, and led the rabbi into a room containing a group of famished, desperate people sitting around a large, circular table. In the center of the table rested an enormous pot of stew, more than enough for everyone. The smell of the stew was delicious and made the rabbi's mouth water. Yet no one ate. Each diner at the table held a very long-handled spoon – long enough to reach the pot and scoop up a spoonful of stew, but too long to get the food into one's mouth. The rabbi saw that their suffering was indeed terrible and bowed his head in compassion. "Now I will show you Heaven," said the Lord, and they entered another room, identical to the first---same large, round table, same enormous pot of stew, same long-handled spoons. Yet there was gaiety in the air: everyone appeared well nourished, plump and exuberant. The rabbi could not understand and looked to the Lord. "It is simple," said the Lord, "but it requires a certain skill. You see, the people in this room have learned to feed each other!" (p. 13).

authority/parental figures, peer/sibling figures, deep personal revelations, strong emotions, and deep intimacy as well as hostile, competitive feelings” (p. 15). In some ways, these dynamics can play out in any group setting (Forsyth, 2010). The therapeutic goal of group therapy is focused on the corrective potential of this recapitulation. The women in this study described the development of intimate relationships within their groups and how this increased their comfort with disclosure of personal information and increased their trust in the group’s commitment to confidentiality. Yet these descriptions were conceptually different from the recapitulation of the primary family group described by Yalom. There was no goal within CenteringPregnancy that was aimed toward recapitulation of the primary family group for therapeutic purposes. However, several women discussed the meaning of privacy to them as being rooted in experiences in their family of origin.

Development of socializing techniques. Yalom (2005) emphasized the opportunities that long term group participation provided for group members to use and develop highly sophisticated social skills: attunement to group process, responsiveness to others, and conflict resolution. He asserted that senior group members are “less likely to be judgmental and are more capable of experiencing and expressing accurate empathy” (p. 17). While CenteringPregnancy groups are time limited, generally 8–10 sessions plus a reunion gathering, other long-term models of group healthcare may allow for the development of more ongoing relationships (Noffsinger, 2009).

Imitative behavior. Yalom (2005) made note of how mentoring is a role that can be fulfilled by both the group therapist and members of the group (p. 18). He suggested that the importance of imitative behavior in the therapeutic process has been underestimated. He pointed to the work of Albert Bandura regarding social learning and his experimental demonstration of the effectiveness of imitation in his discussions (Bandura, 1969). This imitative behavior factor may be reflected in the descriptions of learning from the sharing of others provided by the women who participated in this study. That is, as the CenteringPregnancy group facilitator modeled respect, the members of the group could have become involved in an imitative process, although not explicitly for therapeutic psychosocial skill building or gains as in psychotherapeutic group contexts.

Interpersonal learning. Yalom (2005) devoted an entire chapter to the importance of interpersonal learning. He grounded his discussion in three concepts: the importance of interpersonal relationships, the corrective emotional experience, and the group as social microcosm (pp. 19–52). For the context of group healthcare, the nature of this factor is reflected in the meaningfulness of the learning that occurs within the group. It is more than passing around knowledge from one group member to another, but a generation of group knowledge from synergistically learning together. This process of contextual learning is akin to the educator Freire's (1972) understanding of *Conscientização*, a group process he claimed leads to empowerment. This group knowledge depended upon the process of sharing. Group knowledge relied on the group sense of privacy. In

this research study, there were ample quotes that supported the claim that group knowledge and empowerment were facilitated through the experience of privacy.

Group cohesiveness. Yalom (2005) emphasized the centrality and importance of group cohesiveness in a group psychotherapeutic contexts by addressing this therapeutic factor in a separate chapter (pp. 53–77). In brief, his description of group cohesiveness incorporated the need for belonging, or the belonging factor. It encompassed how group participants develop a sense of being part of the group and how they demonstrate their commitment to the group as a whole. Group cohesiveness included the feeling that one is a respected member of the group. In this study, the women emphasized the importance of respect for privacy within their descriptions of a general sense of respecting within the group that enabled them to share information they considered private with members of the group.

Catharsis. The process of expressing intense emotions was understood by Yalom to be a therapeutic component to the extent that it leads to or catalyzes learning about oneself or others (Yalom, 2005, p. 90-91). The sharing of feeling within a group also contributed to the sense of group cohesion. In this study, when women were asked to recall a group event that made them glad they chose to participate in CenteringPregnancy, many of the participants described experiences of sharing emotions. Many participants also mentioned the benefits of being able to share their experience as new mothers at ongoing group

gatherings after CenteringPregnancy had formally ended, thus continuing the benefit beyond the group encounters.

Existential factors. Most of the therapy groups included in Yalom's (2005) integration of clinical experience, teaching, and research aspire towards personal change as a goal. What he identified as existential factors were rated as highly important by an extensive variety of participants in group therapy (p. 99). The existential concerns addressed included "responsibility, basic isolation, contingency, the capriciousness of existence, the recognition of our mortality and the ensuing consequence for the conduct of our life" (p. 98). The women in this research study expressed their appreciation for the time and opportunity within the group to express these existential concerns. Coping with pregnancy is ultimately about coping with change on multiple levels – physical, emotional, social, and spiritual as the women are engaged in bringing new life into the world and the various responsibilities that come with being a parent over the life-course. Traditional individual prenatal care primarily focused on monitoring the physical. One of the reasons the women in this study chose group prenatal care is that they wanted care that addressed other aspects of becoming a parent beyond monitoring the physical.

Most models of group healthcare explicitly approach the group as a supportive educational environment and do not claim psychotherapeutic goals. However, the theory about group psychotherapy does have relevance to the provision of group healthcare. An appreciation for the goals of group healthcare

can serve to clarify the processes that generate the benefits of group participation and the group dynamics that make them possible. Yalom (2005) emphasized the dynamic and interrelated nature of the therapeutic factors as both functioning as mechanisms for change and creating the conditions that enable change to emerge.

This summary is based on Yalom's (2005) descriptions of the therapeutic factors outlined above, interwoven with the benefits of group healthcare described by the women participating in this study. Given the nature of pregnancy and childbirth, these benefits were different in terms of emphasis and scope than one would logically expect of therapeutic factors within psychotherapy groups. However, common aspects of group dynamics may be shared in several types of groups.

The friendships and increased group intimacy that the women described in this research study were related to Yalom's therapeutic elements of socializing, interpersonal learning, altruism and group cohesion. Comradery, in the sense of women's sharing the experience of pregnancy together, was found to be similar to the therapeutic element of universality. The women in this study expressed their appreciation for the opportunity to share the experience of pregnancy and birth, which are certainly existential human experiences as described by Yalom.

Women in this research also discussed that their fear and anxiety were lessened by being able to share their concerns with each other within the safety of a trusting and respectful group. This finding can be considered an example of Yalom's description of moving from despair to hope through participation in a

psychotherapy group. Instillation of hope viewed through the lens of Yalom's therapeutic factors can engender a positive approach to the experience of birth and motherhood. At the same time, the sharing the women discussed validated the challenges and difficulties they encountered and provided access to the wisdom of the group as a whole.

Limitations.

This phenomenographic study of the experience of privacy for women participating in CenteringPregnancy groups was intended to expand descriptive and conceptual understanding of privacy beyond the protection of personal health information required of individual care. The implications of the findings of this study are limited by several concerns, including setting and sampling considerations.

The women in the study were primarily over 30 years of age, formally educated beyond high school, Caucasian, and living in an urban or suburban area. Additional research into the experience of privacy for younger women, less educated women, women from rural areas, and women from more racially and economically diverse communities might bring substantially different findings to our understanding of the experience of privacy. Philippi and Myers (2013) and Novick et al. (2013) emphasized the need for providers to understand the community context of care during the implementation of group models of healthcare.

None of the women interviewed for this study reported that participating in group healthcare violated their sense of privacy. Nor did they report knowing of any instances of privacy violations within their groups. However, several aspect of the selection criteria may have excluded women who had a more negative experience. First, women were recruited who had attended at least three CenteringPregnancy sessions. Therefore, women who returned to individual prenatal care after attending one or two sessions were not included. Secondly, the CenteringPregnancy providers excluded women they believed would not be good informants for medical or social reasons. The privacy experience of these women may have been markedly different. As Smokowski et al. (1999; 2001) pointed out, most researchers who have investigated group care have selected subjects who experienced some amount of group care. This selection criterion of a minimum amount of group experience ensured that study participants could speak to the experience of group healthcare. However, this criterion could have excluded from the study those individuals who who left their group prematurely. As an example, an individual who attended two group sessions was not included as the criterion was set at three.

Another limitation of the study is that the findings represented the patient experience of women during an episode of pregnancy. Pregnancy and birth in the US involves extensive interactions with the healthcare system. Yet pregnancy is not an illness, but rather a physiological process developing over approximately nine months that is completed in birth. This physiological experience of

pregnancy and birth is embedded in a socio-cultural context. Individual women experience it as a life transition with psychological and social implications (Kitzinger, 2011; Varney, Krebs, & Gregor, 2004). The privacy experiences of persons participating in other models of group healthcare -- addressing chronic illness, episodic surgical specialty care, or preventive primary care needs -- would be expected to be both similar and different from the findings in this study.

Implications for Nursing Practice

Nurses, advanced practice nurses, and midwives are members of healthcare teams using group healthcare to address the needs of the communities they serve. The findings from this research study support best practices that can be incorporated into how patients are recruited into group healthcare, how providers facilitate groups, and how privacy experience is evaluated in an ongoing fashion to improve local implementation of group healthcare models.

Informed consent and recruitment into group healthcare should include not just a written confidentiality agreement, but also a description of how confidentiality is managed in the group and the availability of alternative, more private modes of communication and individual care and referrals. The description of the group should include information about what group participation entails, including which components of physical exams are conducted in group space, provisions for physical privacy, commonly shared health information (such as glucose screening in groups of patients with diabetes), and the risks of a breach of confidentiality that are inherent in any group.

Most group healthcare involves voluntary participation on the part of patients however in some settings enrollment in group healthcare involves a potential element of coercion. This can be subtle, for example when group care is used to improve access -- a group visit may be available in a few days compared to an individual visit in weeks or months (Noffsinger, 2009). Group participation can be a component of mandatory or recommended treatment, for example in buprenorphine treatment for substance abuse (Suzuki et al., 2015). In these situations, special care must be taken to minimize the risks resulting from breaches of confidentiality or suboptimal protection of privacy.

The women in this study clearly expressed that, for them, the benefits offered in the group setting were worth relinquishing some of their privacy and taking a small risk of a breach in confidentiality. They offered a nuanced understanding that having more time with their provider and participating in group discussions enabled the valuable sharing of personal feelings, concerns, and experiences despite the less private nature of a group setting. Recruitment materials such as brochures or videos might make use of patient quotes to illustrate the possibility of this experience when obtaining care within a group healthcare setting.

The special protective role and responsibilities of the provider as group facilitator is another finding with implications for practice. All members of the healthcare team must have some basic skills and understanding of group dynamics. Group facilitators need to develop strategies that balance a less

hierarchical, more empowering and egalitarian approach to leadership with the responsibilities of managing confidentiality and fostering ongoing protection of an ethic of privacy within the group.

The study findings include examples of specific actions taken by group facilitators that enhanced privacy within the group. These actions must be ongoing in response to the process and dynamics of the group and may include:

1. Modeling how to request permission before sharing personal information.
2. Inviting rather than requiring participation in sharing within the group.
3. Encouraging ethical group communication styles.
4. Clarifying the boundaries of the group.
5. Enlisting the group in establishing explicit group norms.

Finally, assessment of confidentiality and privacy experiences should be included in the evaluation of the group. In particular, establishing a mechanism for follow-up and making an effort to reach out to patients who leave the group and include them in the evaluation process could fill in the gap of negative experiences often missing in program evaluation and group healthcare research.

Implications for Nursing Research and Future Scholarship

The findings of this study can be added to our understanding of the patient experience of privacy within group care and in general. This study also demonstrated the usefulness of a phenomenographic research methodology to

address qualitative research questions, clarifying our conceptualizations of the phenomenon of interest and deepening our understanding of the dynamics and interrelationships of concepts.

Additional studies that include a more diverse sample of women and participants of other models of group healthcare would expand the understanding of the experience of privacy in these contexts. One difference between CenteringPregnancy and other models is the relative continuity of the group over the course of pregnancy. This contrasts with more drop-in models that do not provide the opportunity to foster relationships among group members over time.

Research that focuses on interviewing providers about their experience of privacy and confidentiality in the groups they lead would provide a complementary understanding by allowing their perspective to be incorporated into a description of group privacy. Comparison of provider and patient experiences and understanding of privacy is another fruitful area of research. Existing literature contains intriguing references to changes in the patient-provider relationship that occur during group healthcare and deserve further exploration (Baldwin & Phillips, 2011; Jaber et al., 2005; Lavoie et al., 2013; Noffsinger, 2009; Novick et al., 2012).

Other productive lines of research would be to study patients who chose not to use group healthcare or who leave a group prematurely. The perspective of patients who chose not to use group healthcare would assist in addressing privacy issues during the recruitment process. Studies of patients who leave group

healthcare may provide guidance about preventing harm created by breaches of confidentiality.

By continuing to build upon the work of others including Mazer (2011, 2012), Wong and Lavoie (2013), and Novick (2013), researchers should focus their research on investigating the particulars of patient experiences of privacy that will enable us to broaden our conceptualization of privacy. This is important scholarship that opens up the possibility to improve how we address needs for privacy by our patients and can provide specific guidelines for our ethical obligation to protect confidentiality. Holding the patient's experience in the center of how we conceptualize privacy reminds clinicians that our tacit understandings are not always congruent with those we care for. Increasing our understanding of the experience of privacy will enable us to minimize harm while extending the benefits of group healthcare.

Implications for Nursing Education

Nurses and midwives, as members of collaborative teams of providers offering group healthcare, are required to have the skills and experience to manage group confidentiality and protect privacy competently within a group setting. As discussed in the section on clinical practice and based upon the findings of this study, providers need to know the following to provide safe and satisfying group healthcare:

1. Recruit appropriate patients and voluntarily enroll them with adequate informed consent.

2. Create spaces that allow group healthcare participants to retain control of their personal health information as they desire and share only as they chose.
3. Acquire skills pertaining to group dynamic, most importantly the explicit asking of permission before sharing personal information within the group.
4. Understand the importance, from the patient's perspective, of the ongoing experience of the keeping of confidences and asking permission within the group and recognize how this creates the group ethic of privacy.

So how can students acquire the knowledge and experience that will enable them to provide care competently while protecting patient privacy in a group healthcare setting? First, students in nursing and other healthcare professions need a solid understanding of the essential ethical nature of privacy. Patient privacy is one of the core elements supporting the human dignity of all people. Protecting patient privacy demonstrates respect for the whole person and is critical to providing patient-centered care. However, carrying out the mandate to protect patient privacy in a group healthcare setting requires particular knowledge and skills.

Some of these skills may already be part of educational programs that include content that addresses patient education in a group context. In addition, students need theory and experience learning about group dynamics and how to

protect privacy while providing group care. These skills include designing groups with clear goals, recruiting appropriate patients, creating welcoming group spaces that allow for some privacy, facilitating group dynamics, and managing group boundaries (Yalom, 2005). As for most complex clinical skills, a multifaceted approach to teaching and learning--including case studies, role playing, and clinical supervision--would best support the incorporation of these skills into practice.

Placements in clinical sites that offer group healthcare can serve to enhance didactic education about group dynamics. As nursing education and curriculum revisions focus more extensively in the present and near future on interdisciplinary education, midwifery, nursing, and medical students can be integrated successfully into groups that cover foundational concepts that cut across professional practice knowledge and disciplinary foci. For example, the supervision of nursing and interdisciplinary healthcare students participating in group healthcare should include explicit attention to the knowledge and skills needed to manage group confidentiality and maintain a sense of privacy while offering group healthcare.

Finally, organizations that implement group healthcare can provide ongoing training for new group facilitators and staff. This should explicitly address the dynamics and management of privacy for everyone on the team – physicians, nurses, midwives, other providers, medical assistance and other support staff. Ongoing supervision and advanced facilitation skills can be

provided in informal and formal ways. This can include observational evaluation of group process with feedback for the entire team. Advanced group facilitation skills can be offered as continuing education courses or staff development on a periodic basis.

The Healthcare Practice that provided the site for the data collection in this study had developed an approach to ongoing supervision and advanced facilitator training for the providers and staff involved in CenteringPregnancy. This is one example of how supervision and continuing education might be accomplished within a healthcare organization that has chosen to offer group healthcare. On a quarterly basis, after another departmental meeting for clinicians, the providers and staff involved in CenteringPregnancy met over lunch for a two-hour facilitator training. More experienced providers led discussions about approaches to particular subjects and issues that worked well for them, enabling the dissemination of best practices. In a format similar to the CenteringPregnancy or Cooperative Healthcare Clinics models, group discussion topics were chosen by the participating staff. Topics relating to privacy and protection of confidentiality were commonly part of participatory presentations that addressed difficult issues that came up in CenteringPregnancy groups, like pregnancy complications, domestic violence, history of sexual abuse and childhood trauma, and other sensitive topics. This format allowed the CenteringPregnancy coordinate to provide education that addressed the gaps in skills of newer staff as well as share the wisdom of more experienced facilitators across the organization.

Implications for Policy

The women in this study provided rich, detailed descriptions of the benefits they experienced by participating in CenteringPregnancy. As explicated in Chapter Four, these benefits included friendship, comradery, a lessening of fear and anxiety, and contextual learning from all the members of the group. The group dynamic of sharing within the group was found to be a primary mode of group participation. And as described and conceptualized by study participants, sharing within the group was dependent on a group ethic of respect for privacy and confidentiality that allowed for the development of trust within the group over time.

This study demonstrated that privacy is a process that enhances the agency of individual patients to manage and control their personal information in partnership with their providers and the healthcare system as a whole. This understanding reveals the need for changes in at least two areas of policies for the protection of patient privacy. The first is how narrowly privacy is interpreted within HIPAA regulations. Too often, due to HIPAA, patient privacy policies focus on limiting access to personal identifiers and meeting the requirements of notifying patients about organizational policies with respect to the sharing of electronic records for insurance and billing purposes. As evidenced by the findings in this and other studies (Mazer, 2011; Smokowski et al., 2001; Wong et al., 2013), patients experience privacy and its absence or violation in more complicated ways than are addressed by HIPAA regulations. HIPAA does not

take into consideration any of the environmental or bodily components of privacy that clearly mattered to the women in this study and other patients who have been asked about their experiences of privacy (Deshefy-Longhi et al., 2004; Mazer, 2011; Moskop et al., 2005).

Patients expect providers to protect their privacy, but this is more than simply keeping identifying patient information confidential. Incorporating broader and deeper understandings of what privacy means to patients and how it is experienced in different contexts of healthcare can enhance provider-patient communication and better protect the privacy rights of patients. For example, the women in this study described ways in which CenteringPregnancy was *private enough* for them. This concept of private enough is dynamic, changing with health status, group membership, or the sensitivity of the personal information a woman considered sharing. A provider with an ongoing relationship with a patient is in the best position to assess their individual privacy concerns and needs and generate strategies to address these in partnership with the patient. This important, collaborative work lies outside of HIPAA guidelines but matters a great deal to patients and providers. As summarized by Deshefy-Longhi et al. (2004),

Privacy and confidentiality encourage patients to share sensitive information with their primary providers without fear of it being shared with others who are not involved directly with their care. Conversely, if patients do not believe that their conversations will be kept private or that

their information will be kept confidential, they may be hesitant to disclose information fully, and their care may be compromised (pp. 391-392).

A second policy concern related to the static and limited definition of privacy within HIPAA is how protection of privacy is measured, and therefore valued, within current measurements of patient experience and satisfaction with care. As metrics have been developed to evaluate patient experience and linked to hospital and provider performance evaluation and payment the measurement of the patient experience has increased in importance (Wolf & Palmer, 2013). As noted in the review of the literature, there is ongoing controversy about when and how to measure the patient's experience. The issue of when is relevant because a patient may not discover a breach of confidentiality within the week after a healthcare encounter, the time often allotted for sampling patient encounters in hospital and outpatient settings. And a negative response to a question about privacy violations tells little about the setting and personnel involved and therefore provides inadequate information to remediate the situation and prevent it from reoccurring. A dynamic concept of privacy can contribute to quality improvements as organizations develop ways to assess and respond to negative patient experiences that augment standardized questionnaires.

When appropriately implemented to protect patient privacy, group healthcare offers an opportunity for nurses and other healthcare professionals to provide care that is relationship based and satisfying to patients. Therefore, an

additional policy issue would be to expand the use of this innovative approach to improve the quality of life, reduce suffering, and promote health for a greater number of patients. Expanding the use of group healthcare will require removal of some of the barriers to successful implementation.

The fee-for-service model of healthcare reimbursement is one barrier to the expanded use of group healthcare. Two of the models of group healthcare that originated and thrived in the context of managed care organizations have not spread as successfully as the Shared Medical Appointment model. The growth of Accountable Care Organizations (ACOs) under the Affordable Care Act of 2010 could provide the opportunity to expand access to the benefits of group healthcare. The ACO spreads costs across a coordinated network of hospitals, primary care providers, specialists, and community services. Within this model, financial incentives that account for long-term cost benefits through preventing illness and optimizing clinical outcomes could make the investment in group healthcare models worthwhile.

Finally, group healthcare may offer one approach to providing primary care services and prenatal care that addresses some of the barriers in the present system of care that have led to current health inequities. As Browne et al. (2012) noted,

Broad-based PHC [primary health care] approaches and interventions – that integrate accessible, high quality, responsive services with structural and policy changes to improve people’s access to the social determinants

of health – may therefore be one of the most effective means of working towards greater equity (p. 2).

Group healthcare is one approach that can meet this need for accessible, high-quality and responsive care. These benefits depend upon a foundation of patient privacy that is recognized by patients and protected by healthcare providers and the healthcare system as a whole. The findings of this study contribute to a better understanding of dynamics of privacy within group healthcare and offer specific ways to achieve this goal.

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Appendices

APPENDIX A – Confidentiality Agreement

Centering[®]

Confidentiality Agreement

*Privacy is something everyone is concerned about
when they come for group healthcare appointments.*

You should only share information that you feel comfortable sharing with others. You have the right to expect that what is said here will stay private and confidential. Along with our commitment to maintain your privacy, you also have a responsibility to respect and protect each other's privacy.

You may share useful information outside the group, but names or any personal information that you hear or learn about individual group members should not be discussed with anyone else.

Printed Name _____

Signature _____

Date _____



APPENDIX B – Facilitator Email

Date:

Dear

We are writing to you because you have facilitated CenteringPregnancy Prenatal Appointments. We would like to request your assistance with a qualitative research study investigating the patient experience of privacy while participating in group healthcare.

Laurie Friedman, CNM, MSN, is a doctoral nursing student at the Boston College, Connell School of Nursing. [REDACTED], coordinator of clinical nursing education and is the [REDACTED] Principal Investigator for this study. The study has been approved by Laurie's Doctoral Dissertation Committee at Boston College, [REDACTED] [REDACTED] Human Studies Committee and Boston College Human Subjects Research Institutional Review Board.

This study involves interviews with patients exploring their experiences with group care and their privacy experience. We would be happy to share additional information about the study protocols, consent forms and interview guide if you are interested.

What we need your assistance with is reviewing a list of your patients who have attended at least three CenteringPregnancy Prenatal Appointments in the past twenty-four months. You will be asked to exclude women from receiving a letter to participate in the study due to social or health considerations.

Women's participation in the study will involve an initial interview for about an hour. Interviews will be arranged at a time and [REDACTED] site convenient to the patient, will be either by phone or in person, and will be recorded. De-identified transcripts of the interviews will be used for data analysis. A few patients will be approached to review transcripts and to participate in follow-up interviews.

We have generated a list of your patients who have met the study criteria. This list will be sent to you as an [REDACTED] in order to protect patient confidentiality. Laurie would

like to review this list with you for your input into which patients you would recommend be invited to participate in our study. This review can be conducted by telephone or in person, whichever method works best for you. Our goal is to conduct around 10 to 20 interviews with Centering patients.

Laurie Friedman will be contacting you shortly to arrange for a phone call or meeting lasting no more than 45 minutes. You can reach her by email at [REDACTED] or by telephone at 857-756-5456. Thank you very much for your consideration.

Sincerely,

Laurie Friedman, CNM, MSN

Doctoral Nursing Student

Boston College, Connell School of Nursing

[REDACTED]
[REDACTED]
[REDACTED]

APPENDIX C – Study Fact Sheet



Boston College Connell School of Nursing

Patient Experience of Privacy While Participating in Group Healthcare

STUDY FACT SHEET

Laurie A. Friedman, CNM, MSN
Boston College Connell
School of Nursing
Doctoral Student

[REDACTED]
Nursing Education Coordinator
Nurse-Practitioner
Principal Investigator

CenteringPregnancy is a model of group care that aims to improve health by providing patients more time, care coordination, support and learning. Many patients rate their group care experience highly and express their enthusiasm by returning for group visits. However, there are many things we do not know about the patient experience of group healthcare.

CenteringPregnancy is an innovative approach that move care out of the privacy of the exam room. Group visits include written confidentiality agreements by patients and opportunities for individual care according to the needs of the patient. The purpose of this study is to further describe how patients receiving care in groups think and feel about their privacy as one important aspect of their healthcare experience.

Patient Interviews

Patients participating in group care will be contacted by an introductory letter describing the study, a Study Participant Information Sheet and a Permission-to-Contact form to return to the researchers if they are willing to consider participating in the study.

Laurie Friedman will contact patients who agree to be interviewed, and arrange for the time for the interview by telephone or in person at a [REDACTED] center. The interview will include questions about feelings and thoughts about patient's experiences during group healthcare. The interview will take about an hour and will be recorded. Some patients will be asked to review a transcript of their interview and to clarify or add information in a follow-up interview. Written transcripts of the interviews, with identifying information removed, will be used to create a report describing patient experiences. No individually identifying information will be included in the report, but actual words of patients may be used to highlight patient voices. The [REDACTED] Human Studies Committee and the Boston College Human Subjects Institutional Review Board have approved this study.

All confidential patient information will be securely stored at the central administrative offices of the Department of Obstetrics and Gynecology at the [REDACTED].

APPENDIX D – Participant Invitation Letter



Boston College Connell School of Nursing

July 28, 2014

Dear CenteringPregnancy Participant,

We are writing to you because you have participated in a CenteringPregnancy group sometime in the past twenty-four months. We would like to invite you to be interviewed as part of a research study about the patient experience of privacy in the setting of group care. The interview is voluntary and your decision about whether or not to participate will not affect your relationship with [REDACTED].

The initial interview will consist of a set of open-ended questions asked by Laurie Friedman, the researcher conducting this study, focusing on your experiences of privacy while participating in group care. The questions will explore your experiences, thoughts and feelings about various aspects of your privacy. The interview will take about an hour, will be arranged at a time convenient to you, and will be recorded. It can be conducted either by phone or at a [REDACTED] [REDACTED] site convenient to you. Typed transcripts of the recorded interviews without identifying information will be used for data analysis. If you would like, you may receive a transcript of your interview. No information from your medical record will be accessed or used in the study.

This study was designed by Laurie Friedman, CNM, MSN, a doctoral nursing student at the Boston College Connell School of Nursing and a nurse-midwife at [REDACTED]. [REDACTED] is the Principal Investigator for this study as well as the coordinator of clinical nursing education and a women's health nurse-

practitioner at [REDACTED]. The study has been approved by the [REDACTED]
Human Studies Committee and Boston College Human Subjects Research Institutional Review
Boards.

Enclosed is a **Study Participant Information Sheet** with additional details
about the study, what your participation involves and your rights as a study subject. If you are
interested in being interviewed or receiving more information about this study, please return one
of the enclosed **Permission to Contact** forms in the stamped envelope to:

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Please keep the second form and the **Study Participant Information Sheet** for future
reference.

While there is no direct benefit to you from participating in this study, it is our hope that
the findings will contribute to improving the group healthcare experience for future patients. As a
token of our appreciation for your time, upon completion of the interview, we can offer you a \$15
gift card. We very much appreciate your consideration and hope to be in contact with you soon.
If you have questions about your rights as a research participant, please call the Human Studies
Committee at 8 [REDACTED].

Sincerely,

Laurie Friedman, CNM, MSN
Doctoral Nursing Student
Boston College, Connell School of Nursing
[REDACTED]

[REDACTED]
Principal Investigator
[REDACTED]
[REDACTED]

APPENDIX E – Participant Information Sheet



Boston College Connell School of Nursing

STUDY PARTICIPANT INFORMATION SHEET

Study Title: PATIENT EXPERIENCE OF PRIVACY WHILE PARTICIPATING IN GROUP HEALTHCARE

Please read the following information carefully. It tells you important information about the study and how to contact the researchers in the future. Keep this information for your records. Taking part in this study is up to you. Laurie Friedman, a doctoral nursing student at Boston College, also will talk to you about the study at the time of your interview and answer questions you may have.

What is the purpose of this research study?

- The purpose of this research is to investigate privacy as experienced by patients who participated in the CenteringPregnancy model of group healthcare and to generate knowledge about how group healthcare affects the patient care experience.
- This research has no external funding.

How long will I take part in this research study?

- If you chose to participate in the in-depth interview, you will be asked to provide the researcher with contact information and allow them to contact you to set up an appointment for an interview by telephone or in-person.
- The interview will be arranged for a time convenient to you and the researcher.
- The initial interview will take approximately 1 hour, with additional time required if you agree to a follow-up interview in one-two months.
- It will take from one to three months to complete your part in the study.

What will happen in this study?

If you complete the *Permission to Contact* form with your contact information the researcher will get in touch with you in the manner you prefer, either by phone or email, to arrange a time for an interview.

- Interviews will be scheduled at a time convenient to you. The interview can be conducted by phone or at [REDACTED] location of your choice. The interview will be recorded on a digital recorder and you will be asked to complete a brief participant information form.
- A written transcription of the interview will be used for data analysis after your identifying information has been removed or modified with replacement identifiers.
- A copy of the transcript will be given to you if you wish to receive one.
- One or two months after the initial interview the researcher might contact you to arrange a second, follow-up interview.

What are the possible risks and discomforts of taking part in this study?

- There is a small risk of loss of confidentiality through unauthorized disclosure of data whenever personal or medical information is collected for research.
- You may feel uncomfortable answering some of the questions. You may choose not to answer any of the questions at any time during the interview.

What are the possible benefits of taking part in this study?

- Being in this study will not benefit you personally.
- Information from this study may benefit future patients who participate in group healthcare.

What happens if I decide not to take part in this research study?

- Your participation in this study is completely voluntary.
- If you decide not to be in the study it will not affect in any way your medical and health care or health care coverage.

Will it cost me anything to be in this research study?

- The cost to you of participation in this study will be the time spent during the interview and traveling to the interview site if you chose to be interviewed in person.
- At the completion of the interview process, you will be eligible to receive a \$15 gift card.

How will you protect my privacy?

- Federal privacy rules (HIPAA) requires us to protect the privacy of health information that identifies you. This information is called Protected Health Information (PHI).
- Your name will be separated from the data used in the analysis of the study. A pseudonym will be used to replace your name on the transcripts of the interview
- We will follow federal and state laws to protect your privacy and the confidentiality of your participation in this study.

How will my health information be used for research?

- The purpose of this study is to understand how group healthcare affects the patients' experience of privacy.
- Your name, address, the dates of your CenteringPregnancy Prenatal Appointments and your provider's name were used to determine your eligibility for the study and initial contact. This information is not included in the study.
- Your name and the date of the interview will be listed in documents recording your participation in the study.
- Individual identifying information will not be included in the data used for study analysis.

What health information will be used or disclosed?

- Your Personal Health Information (PHI), your name and the date of the visit, will be listed in documents recording your participation in the study, but will not be included in the data used for study analysis
- The information you provide on the permission to contact form will be used to contact you about follow-up interviews, provide you with a transcript of your interview and a report of the study findings if you choose. This contact information will not be connected with your interview transcript for the purpose of data analysis.
- Quotes from your interview will be used, but without identifying personal information.
- No personal health information will be disclosed without your permission.
- The results of this study will be reported in the doctoral dissertation of Laurie Friedman, CNM, MSN. Study findings may be published in a professional book or journal, or used to teach others. However, your name or other identifying information will not be used for these purposes.

Who may use my health information?

- Laurie A. Friedman, CNM, MSN, Boston College, Connell School of Nursing
- [REDACTED]
[REDACTED].
- No protected health information will be disclosed to persons or organizations outside of [REDACTED].

When will you stop using my information?

- The research data collected during this study will be kept for at least six years or until after the study is completed, whichever is longer.

Right to withdraw

You can withdraw from this study at any time. You can phone, email or write to the researcher, Laurie Friedman, regarding your desire to withdrawal your participation. See the Contact Information below.

Laurie Friedman, CNM, MSN

[REDACTED]

Phone 857-269-0163

Or you may formally withdrawal by writing or calling the Principal Investigator:

[REDACTED]

If I have questions or problems, whom should I contact?

If you have questions about the **scheduling of appointments or study visits**, call **Laurie Friedman at 857-269-0163**. You may also use email at **Laurie.Friedman@bc.edu**.

You can call the researchers involved with your questions or concerns.

- [REDACTED] is the person in charge of this study. You can call her at [REDACTED]
- Danny Willis, DNS, PMHCNS-BC is the faculty supervising the doctoral research of Laurie Friedman. You may call him at 617-552-6838 or email at danny.willis@bc.edu.

If you want to speak with someone not directly involved in this research study, please call the Human Studies Committee Office at 1 [REDACTED]. You can talk to them about:

- Your rights as a research subject
- Concerns about the research
- A complaint about the research
- Any pressure you feel to take part or continue in a research study.

APPENDIX F – Permission to Contact Form



Boston College Connell School of Nursing

STUDY TITLE: **Patient experience of privacy while participating in group healthcare**

PRINCIPAL INVESTIGATOR: [REDACTED]

CO-INVESTIGATOR: **Laurie A. Friedman, CNM, MSN**

PERMISSION TO CONTACT PATIENT FORM

I am a [REDACTED] patient who has participated in at least three CenteringPregnancy Prenatal Appointments in the past twenty-four months.

I may be interested in being interviewed as part of a research study conducted by Laurie Friedman, a certified nurse-midwife (CNM) and doctoral nursing student at the Boston College Connell School of Nursing and [REDACTED] Principal Investigator, to learn more about my experience with group care and patient privacy.

I give my permission for the researchers to contact me to provide me with additional information about this study and possibly arrange for an individual interview, either in person or by telephone.

I understand that complete confidentiality of phone and email communication cannot be guaranteed. My preferred way to be contacted is by:

☐ **Email:** _____

☐ **Phone:** _____

☐ **Mail:** _____ (Address)

_____ (City, State, Zip Code)

I understand that my signature indicates my agreement to be contacted by the researchers and that I may withdraw my participation in this study at any time. I may change my mind and decide not to be contacted by Laurie Friedman by leaving a message at 857-269-0163, emailing Laurie.Friedman@bc.edu, or calling [REDACTED]. I have received a copy of this form.

Signature

Date and time

Written name

APPENDIX G– Interview Protocol Guide

Patient Experience of Privacy in Group Healthcare

Interview Protocol Guide – Initial Interview

Introduction to the interview.

The following questions I would like to ask you are about your experience with CenteringPregnancy as part of a study investigating patient experience of privacy in group healthcare. I am interested in your experiences – your feelings, thoughts, perceptions and reflections about participating in group care. Please feel free to pause and think about your responses and feel free to tell me that you would prefer not to answer a particular question. You can decide to end this interview at any time. I expect the interview to take about an hour, depending on how much you choose to share about your experiences.

Have you attended at least three group healthcare visits in the prior twenty -four months?

When was your most recent group visit? Please tell me about this visit –

Could you tell me why you chose to participate in CenteringPregnancy prenatal appointments?

Do you recall signing a Confidentiality agreement? Please describe how this occurred.

Do you recall other discussions about confidentiality in the group?

Please tell me how you felt about sharing personal information in the group?

Was there a time you hesitated or chose not to share information?
How did this feel? Please tell me more about this experience.

Can you tell me about a time you felt uncomfortable during a group visit? Please tell me about this time.

Can you tell me about a time you felt uncomfortable during an individual health visit?

Could you describe what you did at the time you felt uncomfortable during a visit?

Are there other examples of this kind of experience during a group or individual visit?

Could you please describe what you did in this situation?

Can you share an example of an experience during a group visit that made you want to continue to participate in group care?

Did you usually attend CenteringPregnancy appointments alone or with someone? Who did you bring to visits?

Did you feel that having family members and friends of other women in the group affect your experience of the group?

Have you had any concerns about your own privacy? Please tell me more about this.

Have you had any concerns about the privacy of others? Please tell me more.

When you think about your “privacy”, what exactly do you mean?

Was there something you needed or wanted regarding your care that you did not want addressed during a group visit? Please describe what you did about this situation.

In general, how would you compare your experience of privacy during group care with privacy during individual care?

Are there aspects of your personal story or identity, for example your age, race, gender or occupation that you think influences what privacy means to you?

Please tell me the ways this is true for you for each characteristic.

Is there something you would like to change about the group visits?

Please tell me anything else you feel might be important to understanding your experience of group healthcare.

THANK YOU FOR YOUR TIME AND RESPONSES DURING THIS INTERVIEW